

# the POWER of ONE



## **Towards a Representation of Unheard and Unseen Individuals in the Hospital, Workplace, and Neighborhood.**

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# Acknowledgements

There are many people who have inspired, stimulated, and helped this research project come about, all of whom we would like to thank. First of all, we are very grateful to the participants in the hospital, workplace, and neighborhood context, who took part in this research project and made it possible. We are thankful for your time, assistance in helping us gain information, and extending our networks, and for the experiences, thoughts, and stories shared with us. Second, we want to thank Niva van de Geer and Vera van Groos from Flatland Agency, who facilitated and monitored our interdisciplinary discussions through digital visualizations aimed at creating a shared understanding to stimulate dialogue between the scholars. The insights gained during these sessions were invaluable to the research process and progress, and inspired us to continue pursuing our research objectives.

We also want to thank the Centre for Unusual Collaborations (CUCo) for believing in this project and for funding it. It is because of daring initiatives such as CUCo that researchers can think outside the box and true scholarly advances can be made. Lastly, we want to thank each other, the researchers involved in this project, for their time, considerations, interest in the subject matter, and their openness for different perspectives that arose during the interdisciplinary discussions. We all underscore the importance of enabling the power of the voices and stories of individuals we are not heard or seen in society. We are driven by the desire to bring about change, and the ultimate wish for a more inclusive society, and believe this can be achieved when different perspectives are brought into conversation with each other. To the readers of this report, we hope you find it an interesting and joyful read, and that it provides novel insights into the barriers to fully inclusive research and advocacy efforts in the hospital, workplace, and neighborhood contexts. Further, we aspire for this report to spark interest and motivation among researchers and professionals so they will continue studying this topic with the aim of developing practical solutions.



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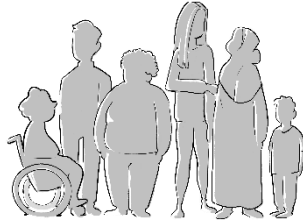
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## Chapter 1. Introduction

There are people who feel a lack of representation in a society that does not hear or see them. These unheard and unseen individuals are often a minority, have an intersecting complexity of social problems, or belong to otherwise marginalized groups that find it difficult to express their needs when policies and procedures are created. Because of this invisibility, they even tend to be overlooked or are simply not reached in efforts aimed at solving the problems they encounter. This is because the people who are interested in solving societal problems, including academics, policymakers and aid workers often focus on what they perceive as the average individual in a group or category. It is often difficult to recognize the needs of those people who (partly) fall outside the groups that are best represented in policy decisions, as a consequence of their unnoticed complex intersectional identity or social situation. As a result, unheard and unseen individuals are likely to be underrepresented in activities related to research, advocacy, and outreach. This impedes the ability to generate policies and procedures that are of benefit to all members in a society. Hence, in order to address societal issues and achieve generalizable solutions, we need to make the invisible visible by empowering their individual stories. This is what we mean by ‘The Power of One’: the idea that a genuine interest in the voice and complex identity of the unique individual will help us, researchers, as well as policymakers and aid workers, to remain sensitive to the human behind the label or category. While in research, advocacy, and outreach activities, it is unavoidable to generalize people into categories, doing this without paying sufficient attention to human individuality will cause significant groups to remain unseen and unheard, hampering the efforts to create policies and procedures that address the needs of underrepresented individuals. The current report covers the first phase of a trans- and interdisciplinary undertaking aimed at identifying which groups of people are overlooked in aid work, policymaking, and research and at pinpointing causes of this issue.

Our collaboration finds its origins in interdisciplinary brainstorming sessions that led to the establishment of the Centre for Unusual Collaborations. In these sessions, researchers from diverse disciplinary backgrounds identified that individuals with intersecting group identities or problems seem to be missing

in research, advocacy, and outreach efforts in the contexts of the hospital, the workplace, and the neighborhood. For this, we relied on our own experiences in these contexts, as well as anecdotal evidence from the professionals we encountered there. In the hospital, medical professionals find that there is a mismatch between the population of patients with rheumatoid arthritis and patients participating in clinical trials. Certain groups are underrepresented in medical research, which hinders effectiveness and safety of new drugs to alleviate or cure rheumatic diseases. In the workplace context, LGBTQI+ (Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex) continue to face discrimination, resulting in their voices to be unheard or are even silenced, and the fact that many of these employees remain closeted at work. In the neighborhood context, certain groups of residents are not engaged in neighborhood health and well-being projects and activities (e.g., sports and social activities). As a consequence, these residents are isolated, or are on the brink of becoming estranged from society. The fact that individuals who suffer from a variety of problems mentioned above remain unseen is an indication that current medical research, as well as efforts in the workplace and neighborhood are far from optimal and require improvement to reach and assist unseen and unheard individuals.

This project is part of the Centre for Unusual Collaborations, and aligns to the center's aim to foster unusual collaborations between researchers and professionals from different disciplines to address major social challenges, in this case, the complex problem of unheard and unseen individuals in the hospital, workplace, and neighborhood context. While the aim seems to be of merely operational nature, that is, to help multidisciplinary academics collaborate, at the core of this aim is a powerful and timely idea: when facing wicked societal challenges, you need to bring diverse minds together and do so in new forms of engagement. We welcome this challenge and shape it towards a dual research endeavor: research methods and approaches of unusual academic collaboration, while grounding this work in concrete societal contexts that exhibit problems worthy of inquiry. At the level of meta-research, that is, researching the (unusual) ways we address the identified challenges, we aim to explore whether collaboration materializes and shows sign of constructive engagement with the subject matter, whether the richness of individual backgrounds leads to academic work that is more than just the sum of its parts, whether the felt need for new methods and approaches is justified, and finally, what the nature of preferred inquiry will be. These meta-research considerations will be revisited in the final discussion. The main body of this report deals with the subject matter of the 'Power of One'. The overarching research question of this study is how can unheard and





unseen individuals in the hospital, workplace, and neighborhood become better represented in (academic) research and advocacy efforts? In this ten-month pilot we aim to:

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- a) investigate the current strategies of identifying the needs of unseen and unheard populations, and;
  - b) assess whether and to what extent these strategies sufficiently reach the individuals within these populations in the contexts of the hospital, workplace, and neighborhood.
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Based on expert knowledge of the different researchers in our study, these research aims are translated into the following objectives for the different contexts. First, in the hospital context, this study addresses the process of patient inclusion in rheumatoid clinical trials and related challenges in this process. Second, in the workplace context, we draw upon strategies employed by Human Resource (HR) managers, Diversity and Inclusion (D&I) officers, and representatives of LGBTQI+ employee networks to assess and address the needs of LGBTQI+ employees in the workplace, so they can be better supported at work. Last, in the neighborhood context, we examine the strategies professionals employ to reach out, support, and engage neighborhood residents in projects and activities, and shed light on the challenges they face in doing so. We should note that the strategies outlined in this report are based on the accounts of our interviewees. Therefore, we do not know if and how these are put into practice by the professionals in the different contexts.

In what follows, we present a methodology chapter, three chapters displaying our findings, a discussion chapter, and an appendix. Chapter two describes the methodological underpinnings of this research. In Chapter three, we discuss the strategies employed by medical professionals to include patients in rheumatoid arthritis medical research and the obstacles professionals encounter. In Chapter four, we discuss the strategies employed by the professionals on diversity and inclusion in the workplace and the representatives of the LGBTQI+ networks to assess the ways in which the needs of the LGBTQI+ employees are measured and taken into account. In Chapter five, we identify the methods used by professionals to engage individuals in neighborhood projects, and discuss related barriers. In Chapter six, we review and synthesize our research findings, provide recommendations based on our analysis and ideas presented by the professionals, and discuss future research suggestions. Taken together, our study takes the first steps towards better representing unheard and unseen individuals in the hospital, workplace, and neighborhood.





## Chapter 2. Methodology

This study is the product of an unusual collaboration between an interdisciplinary group of scholars from different Dutch universities and research fields, ranging from the humanities, social sciences, natural sciences, and applied sciences. Funded by the Centre for Unusual Collaborations, ‘The Power of One’ raises the importance of trans- and interdisciplinary co-creation and sharing of knowledge. The value of interdisciplinary research is that the integration of different perspectives, approaches, and insights enriches the study, leading to a more comprehensive understanding of the problem and data than one discipline could provide. Each of the three subprojects is led by an expert in the specific field. In addition, two scholars from different disciplines, having different perspectives, attitudes, and potential solutions towards the representation of unheard and unseen individuals in the hospital, workplace, and neighborhood context, joined each subproject. Under guidance of the team of researchers, the study was executed by two associate researchers, both with a background in cultural anthropology and expertise in the research methods used to conduct this study.

### 2.1. Research methods

This study took a qualitative approach which allowed us to understand the emic points of view of the research participants, which encompass the way people think, imagine, and give meaning to their lives and experiences (Beuving & de Vries, 2015; Gobo, 2008). Not all researchers involved in this study were familiar with qualitative research methods, particularly in-depth interviews, and thus went out of their comfort zone. The two research associates executing the interviews and the first data analysis have experience in conducting qualitative research, and are experts in the respective methods. The data in this study were gathered by means of two different research methods: desk research on relevant professional reports and academic literature and semi-structured in-depth interviews. First, the data for this study include literary desk research around the themes discussed in the three different contexts. For the hospital, we compared thirty scientific publications focusing on rheumatology to see if there is a possible mismatch between the Dutch population of rheumatoid arthritis patients and the Dutch patient population that participates in clinical trials. For the workplace, the literature research focused on the representation of LGBTQI+ people in large-scale surveys, and specifically LGBTQI+ employees in (Dutch) workplace



research. We examined whether and how intersecting identities were incorporated or overlooked in these surveys. For the neighborhood, we looked into current studies on neighborhood residents' participation in different sports, social, and healthcare projects, and the idea of *zelfredzaamheid* [self-reliance] that has become part of Dutch political discourse.

Second, we conducted multiple interviews with professionals in the three contexts. Participants were recruited through the researchers' personal networks and by using snowball sampling. The semi-structured in-depth interviews were characterized by an open structure, allowing the participants to communicate their feelings, experiences, opinions, and to talk about other topics important to them. Through this format, we obtained rich data beyond generalized statistics of quantitative studies, emphasizing the experiences and perspectives of the individuals. We developed an interview guide with topics and related questions for each context, steering the interviews in the desired direction. We obtained informed consent from the participants. We mostly conducted the interviews online (due to the restrictions of the pandemic) and some in person. The interview length ranged from 30 to 75 minutes. They were recorded and stored in a secure SURFdrive. The audiotaped interviews were transcribed verbatim by the associate researchers. To prevent recognition, we anonymized participants' names and other identifying matters, such as the organization or network with which they are associated. Yet although we did our best, we cannot completely eliminate the possibility of our participants being recognized, due to specific use of strategies, concepts, or approaches.

The study sample included a total of 29 participants varying in gender, age, ethnicity, and profession. First, the context of the hospital involved participants from the rheumatology outpatient clinic of a single Dutch university medical centre. We conducted eight in-depth interviews, including questions about patient participation in clinical trials and the mechanisms that impede or enhance patient participation. The participants included two rheumatologists (one retired and one active in the hospital), a doctor-researcher, a medical doctor, two research nurses, a coordinator of clinical trials, and an advisor for patient participation. Second, for the workplace, we interviewed thirteen participants, namely different HR managers and consultants, D&I officers, a manager of Inclusion and Social Entrepreneurship, a representative of an intersectional interest group, and chairs and board members of the LGBTQI+ employee networks in the respective organizations. The organizations were either mid-sized organizations with up to 250 employees, or large organizations with more than 5000 employees. We asked questions about the current strategies used to assess the needs of LGBTQI+ employees. Third, the context of the neighborhood involved eight participants, including three researchers involved in different neighborhood projects, two representatives of the municipality, a coordinator and representative of a fund, and the local church support in a Dutch city. Questions were asked about the strategies used to reach unheard and unseen individuals in the neighborhood.



## 2.2. Analysis

The analysis for this study was informed by interdisciplinary discussion. Throughout the research process, several sessions took place involving the team members working on one of the contexts. Additionally, monthly sessions were held with all researchers who were part of this project to share knowledge, experiences, and insights. These sessions were moderated by Flatland Agency, a consultancy that employs design-thinking methodology and visual thinking to enable team members to develop a shared language to devise a methodology for trans- and interdisciplinary co-creation. During these sessions, discussions took place on the process and content of our study in the three contexts, cross-fertilizing our knowledge, experiences, and insights, which were facilitated and visualized in graphic drawings by Flatland Agency. The digital visualizations served to communicate about our research process and progress. At the end of this study the visualizations were used as final output, synthesizing our findings and displaying the results. Throughout the report various visuals will be showcased, e.g., a visual to encompass our research on the front page, visuals at the start of every subchapter, and the visuals regarding our process can be found in Appendix 3. Furthermore, these joint sessions helped us to synthesize the information and interpret it. For more on the process of our research project and our interdisciplinary collaboration see our meta-research report (Appendix 1). Aside from the sessions, team members read through the transcripts and chapters of their respective contexts, and shared their thoughts, ideas, and suggestions through their own disciplinary lens. All researchers also read through the interview transcripts and chapters of the other subprojects before engaging in integrative discussions about their content. In this way, we were able to utilize different perspectives of the researchers involved and minimized analytical bias.

Part of the analysis was the coding of the interviews using open and thematic coding methods. The open coding technique is used to identify meaningful categories, themes, and patterns in the research data which are used to label these categories from the transcript (Beuving & de Vries, 2015). This meant that we read the transcripts carefully and divided them into thematic sections. Open coding is then a great analytical handle to conduct thematic coding, where you break up the transcript into pieces, compare them, and assign them to groups that address the same theme (Boeije, 2010). Important to note is that our research process was iterative, meaning that the process of conducting research gave rise to new ideas which, in turn, fed back into the data collection and analysis stage. Decisions made early in the research process were revisited in light of new insights or practical problems encountered. This process of analysis adheres to the grounded theory approach, as it is both inductive and iterative as we shift between data reduction, data display, and data interpretation and verification (DeWalt & DeWalt, 2011).



In analyzing our data, we also highlighted stories told by our participants as found in the transcripts and used some of these to construct short stories. These stories can be found on our project page on the website of the Centre for Unusual Collaborations<sup>1</sup>. This is a way to share our findings with a non-academic audience. In order to do so, a structured narrative interviewing technique was used. This technique was discussed in a conference paper by Moenander and Basten (2015), who explain that the structured narrative interview is a cutting-edge method devised around interview questions that can be used by the researcher “to quickly and adequately gather narratives that can then be analyzed”. The aim is to focus on the story that unfolds by looking at four stages (i.e., manipulation, competence, action, and sanction) that can be analyzed. Although the technique is mostly used in interviews to find narratives in the events talked about, or in the stories shared, it can also be used to extract narratives from the written transcripts of the interviews. We used the latter approach, and looked for certain events shared by the participants and the stories told.

### 2.3. Reflections

Before we go into presenting our findings, we reflect on our own positionality as researchers and our research objective. First, while our research team encompasses a great diversity of disciplines, diversity in terms of demographic dimensions is rather limited. Our team includes men and women in different career stages (from recent MA graduates to full professor), we are all white, mainly of Dutch nationality, abled, and mainly heterosexual. We consider that future research should employ an even more diverse group of researchers in the future and to engage more professionals in our study from the start (see Pharos for the methodological explanation of such future endeavors<sup>2</sup>). Second, we should note that although our study has a larger research aim to work towards the representation of unheard and unseen individuals in the three contexts, this ten month pilot study is limited in scope. In order to move away from having conversations with professionals in the hospital, workplace, and neighborhood context to having conversations with invisible populations in these contexts, we applied for funding to continue this research project. However, the first step towards the representation of the Power of One requires us to understand what strategies professionals use and to what extent these strategies sufficiently reach unheard and unseen individuals in the different domains.

Last, we want to note that some professionals in the neighborhood questioned the importance of our study for their work; what contribution would scientific and scholarly output make to their efforts in social welfare work? On some occasions, this question limited participants’ willingness to take part in our study. We acknowledge that, with our current focus on assessing the strategies used to reach invisible individuals in

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<sup>1</sup> Source: <https://www.unusualcollaborations.com/>

<sup>2</sup> Source: <https://www.pharos.nl/infosheets/inclusief-onderzoek/>



the neighborhood, we do not offer real-world solutions; although this is a future aim of this project. We should add that whereas some professionals questioned our study, others were very interested in the pursuit of our study. They wished to learn more about the ways in which they could reach unheard and unseen individuals in the neighborhood, especially, since they struggled reaching these groups of individuals.

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## Chapter 3. The Hospital

Clinical trials serve to test the effectiveness and safety of new drugs to alleviate or cure diseases of individuals. One of the key determinants in the successful execution of clinical trials is the inclusion of a representative sample of patients who participate in the trial. This is because each individual has their own genetic and demographic characteristics that can influence the efficacy of and response to drugs. The more diverse the group of patients represented in studies, the more generalizable and therefore useful the results will be for real-world care and treatment. Diversity in the sample of patients participating in clinical trials also affects the information that can be extracted from the trial. However, sponsors (e.g., pharmaceutical companies) of clinical trials tend to prefer a more homogeneous sample because this reduces the variance in data, and thereby increases the chance that clinically significant outcomes will be observed (see U.S. Food & Drug Administration, 2018). There is a clear tension between the importance of inclusion of underrepresented groups and the diverse (intersecting) characteristics of individuals belonging to this group, and collecting a narrow selection of individuals in clinical trials.

As Mosenifar (2007) states, there is often a mismatch between the demographics of the patient group enrolled in a clinical trial and the actual patient population, resulting in certain groups being underrepresented. Henceforth, clinical trials cope with population issues, which pose a difficulty for future clinical studies (Mosenifar, 2007; Patel et al., 2003). Dutch statistics show that 60 percent of rheumatoid arthritis patients are women with an average age of 68 (Sloot et al., 2016). The reality, however, is that (Caucasian) women (72 percent) with an average age of 52 are overly represented in rheumatic medical studies (see Baeten et al., 2013; Bakker et al., 2011; Bijlsma et al., 2016; Bon et al., 2014; Burmester et al., 2020; Herrick et al., 2017; Khanna et al., 2018; Khanna et al., 2020; van den Hoogen et al., 2018; van der Kroef et al., 2020; Verhoeven et al., 2020). One reason for the mismatch is that patients' participation in clinical trials is determined by inclusion and exclusion criteria that are often not founded upon an “evidence based scientific justification” (Kim et al., 2021, p. 238), but on practical considerations such as feasibility and availability of the participants instead.



In this subchapter, we aim to identify the challenges to engaging and recruiting a diverse group of patients for rheumatic clinical trials, and identify the barriers that impede or increase individuals' willingness to take part in these trials. First, demographic statistics about patients represented in studies on rheumatic diseases were collected through literary desk research. In addition, in-depth interviews were conducted with rheumatologists (one retired and one active in the hospital), a doctor-researcher, a medical doctor, research nurses, a coordinator of clinical trials, and an advisor for patient participation within academic hospitals in the Netherlands. These medical professionals have varying (in)direct roles in clinical trials and work on blood sample studies, randomized sample studies, randomized placebo-controlled studies, and new drug studies. Important to add is that in many cases, once patients participate in (long-term) clinical trials, they are no longer under the care of their initial physician, but monitored and treated by the (doctor-)researchers and research nurses.

For the rest of this chapter, we first consider the inclusion and exclusion criteria to patient participation in clinical trials. We present a patient flow chart concerning the screening process of patient participation. Then, we discuss the barriers that impede or enhance patient participation in clinical trials (e.g., personal, relational, and assumption-driven barriers). We indicate that these barriers function as mechanisms that complicate patient participation in rheumatological research in a single Dutch university medical centre.

### 3.1. Inclusion and exclusion criteria patient population

An important component in clinical trials are the inclusion and exclusion criteria that specify the characteristics of the patient population who can partake in clinical trials. These characteristics “typically identify a population in which it is expected that the effect of the drug can be shown” (U.S. Food & Drug Administration, 2018, p. 1), and are based on both ethical and scientific considerations. Depending on the clinical trial and its purpose, inclusion and exclusion criteria are formulated, the latter often containing factors that may obscure the results of the study or pose a potentially higher risk to the patient, such as comorbid conditions, old age, and pregnancy. Pharmaceutical companies play a role in defining inclusion and exclusion criteria by drafting the regulations in such a way that they can legally protect themselves (U.S. Food & Drug Administration, 2018). In addition to these formal exclusion criteria, as the doctor-researcher discloses during our interviews, there is a ‘gray area’ in which a patient is eligible for the trial on paper, but is not included as other factors might complicate the interpretation of the study results, such as long-term chronic pain or a lot of osteoarthritis (a condition where the protective cartilage that cushions the end of the bones breaks down). The exclusion of certain patients in clinical trials has great implications for the response to and applicability of the drug(s) being tested.





Our research demonstrates that too limited a command of Dutch is another exclusion criterion. Although many interviewees indicate that all patients can take part in a trial if they meet the formal inclusion criteria, in practice there are additional factors that come into play that influence this inclusion process, for instance when patients are not capable of reading and communicating in Dutch or English (e.g., patients whose mother tongue is not Dutch, or patients that are lowly literate). To the question, “do you inform all patients about clinical trials?”, throughout the interviews it became clear that language is in practice an exclusion criterion as well, as illustrated in the following answer given:

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*Well, no, in principle I try to [inform] everyone, except if there is a language barrier, for example. Then someone simply cannot participate, because then they cannot read the patient information [form] independently. We only have those in English and Dutch. So if someone is not fluent in either language, then someone just cannot participate.*

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As can be seen from this quote, not (fully) mastering Dutch (or in some cases English) and thus not being able to read and interpret the patient information form is an exclusion criterion. The patient information form, or PIF for short, is a document which consists of numerous pages including detailed information about the clinical trial and its risks, which must meet certain standards that are approved by the medical ethics committee. The extent to which this exclusion criterion is applied depends on the medical professional, which makes it rather subjective and thus problematic. Some interviewees decide not to inform the patient about the trial if there is a language barrier. One of the interviewees explains that if, for instance, a Muslim woman speaks poor Dutch, then you know that the questionnaires cannot be completed adequately, “there is a lot of hassle involved, which makes you think that it is not useful to ask this person”.

On the other hand, a few interviewees indicate that in some cases patients with a language barrier can participate in a clinical trial. This is possible if relatives act as non-professional interpreters or if a research nurse entrusts the patient to translate the form and other questionnaires themselves through online translation services (it is important to note that using a relative as interpreter can be a timely investment and emotional burden for relatives, as well as a problem in terms of data protection). It is key that patients understand what the trial is about, and what the involved risks are, especially when applying for more risky experimental clinical trials. One of the research nurses says that this criterion is less strict when it comes to other less risky studies, such as a blood sample study or a study where the drugs have already been approved.

In conclusion, various ethical, scientific, and perhaps practical considerations of medical professionals form the inclusion and exclusion criteria that determine the patient group partaking in clinical trials. Before a patient is enrolled in a clinical trial an extensive screening process has preceded. In the following section,



we demonstrate the different stages of the screening process of rheumatic patients within the hospital. We argue that this process in practice involves additional exclusion mechanisms that can affect the representativeness of the patient sample in rheumatological clinical trials.

### 3.1.1. Screening process rheumatic patients in the hospital

The screening process of (rheumatic) patients in the hospital consists of two phases: pre-screening and a screening visit. In the pre-screening phase, various methods are used to include patients that vary from more reactive methods – where the initiative to inform (or register) oneself lies mainly with the patient – such as information on websites, social media, flyers, and (personalized) letters, to a more proactive approach, through which patients are directly informed about clinical trials by their physician during the consultation. As noted in the interviews, the former methods do not sufficiently reach the entire patient population because, for example, patients do not use the internet or they do not end up on the correct website. In an effort to increase the outreach and accessibility, the hospital is currently developing a mobile application for personalized information about diseases and potential trials, and the use of screens in waiting rooms to display information about current clinical trials.

This current study focuses mainly on the pre-screening process, which concerns the consultations of patients with a physician or doctor-researcher at the rheumatology outpatient clinic of the hospital. If the medical professional encounters a patient who might be eligible for and benefit from a particular clinical trial, they can inform the patient about the possibility to enroll in a trial. This short consultation is intended to make the diagnosis, as well as to explain the next steps in the medical process. A possible treatment plan could be one of the clinical trials currently running in the hospital. As aforementioned, medical professionals use formal exclusion criteria to make a preliminary selection which patients they will and will not inform. Additionally, we identified other, more informal exclusion criteria which are influenced by practical, personal, relational, and assumption-driven barriers, which will be elaborated in the following sections. If patients do meet the broad (in)formal inclusion criteria in this pre-screening process, and if they are willing to participate in the clinical trial or wish to get more information, they are referred to the research nurse.

The second phase of the screening process is the screening visit predominantly executed by research nurses. On the one hand, this screening visit functions as an informative consult in which the medical professional provides the patient with (additional) information about the clinical trial and answers possible questions. On the other hand, the screening visit is used to screen patients in more detail based on the inclusion and exclusion criteria of a particular trial. If the patient is willing to participate and is eligible according to the criteria, the patient is handed a patient information form. The patients are often given time to thoroughly read the PIF and discuss it with relatives before signing the form. During the screening process, different



barriers play a role in patients' willingness to participate in clinical trials, which will be discussed in the following sections. It is important to note that patients participating in the (rheumatoid) clinical trials do not receive a reward or incentive beyond the reimbursement of parking and/or transport costs. According to Vellinga et al., “incentives for patients may be seen as coercive, or as exerting undue influence on potential participants’ decisions about whether to take part in research” (2020, p. 2). Below we present the patient flow chart of the screening process (Figure 1).

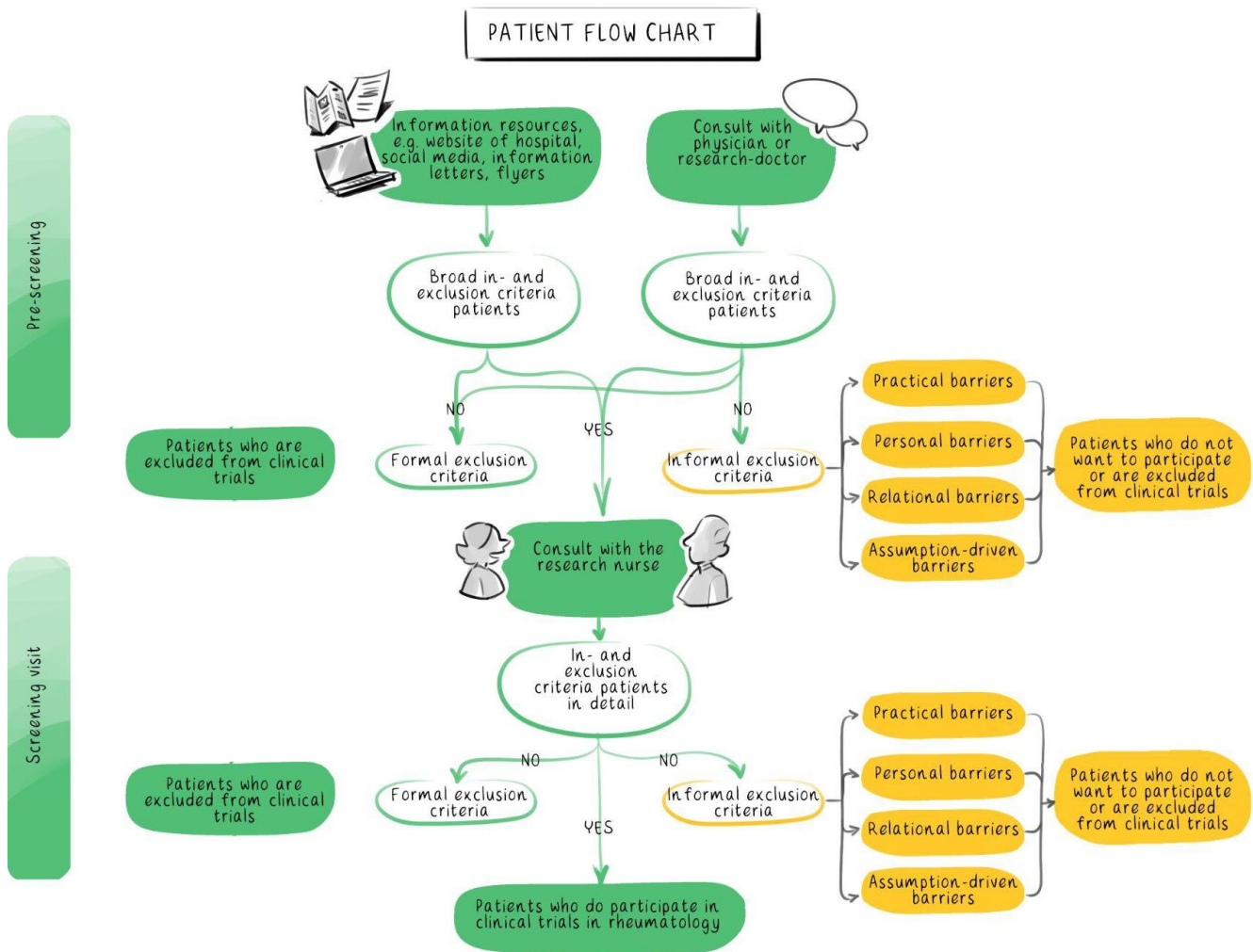


Figure 1: Patient flow chart of the screening process for rheumatoid clinical trials



## 3.2. Barriers to patient participation

### 3.2.1. Practical barriers

In talking to different medical professionals and an advisor for patient participation, we identified various practical barriers for both medical professionals and patients that impede patient participation in rheumatoid clinical trials. First, all participants recognize lack of time and money as a major practical barrier. The enormous workload of medical professionals in combination with short consultations of approximately fifteen minutes with (new) patients often causes appointments to run late. Amongst other things, the diagnosis must be made within a short time, which means that medical professionals have little to no time to inform the patient about the clinical trial. Furthermore, lack of money is a barrier to improving the inclusion process, such as translating the patient information forms and questionnaires or hiring interpreters for non-Dutch speaking patients.

Second, as the advisor for patient participation states, the high turnover of physicians in the academic hospital is a practical barrier: “yes, these changing physicians, that is a real issue for patients in an academic hospital. They really experience that as a breach of trust”. Due to the academic nature of the hospital, staff members, especially assistants, come and go and patients are oftentimes assigned to a new physician. Although the doctor indicates that patients in this hospital are used to seeing different faces during the consultations, he acknowledges that “it would certainly benefit patients’ willingness to participate in research if they have a regular physician”. Moreover, as the rheumatologist adds, having one main physician is not only beneficial for the patient and their well-being, it will also save time in the long run as the logistics are complex.

Third, fewer patients physically come to the outpatient clinic because many consultations are held via phone calls due to the global pandemic. According to the research nurse, it is even more difficult to motivate patients to enroll in clinical trials as a result of this shift from physical to phone consultations. In addition to the impediment of patients’ motivation, the research nurse describes the implication of this barrier from two perspectives. From the medical professional’s perspective, it is complicated to estimate whether the patient’s disease is flaring up, which is often a sign to start another treatment plan, e.g., enrollment in a clinical trial. From the patients’ perspective, the phone consultation may hinder a trusting relationship with the medical professional, which is an important factor in patients’ willingness to participate in clinical trials (see Broekstra et al., 2020; Mosenifar, 2007).

As a result of the aforementioned logistical barriers, the development of a more inclusive patient information form is hindered. Although some interviewees agree that translating and simplifying the PIFs



may ensure that more patients are eligible for and willingly to participate in clinical trials, most of them see obstacles in its implementation. First, the translation of PIFs, along with other forms such as questionnaires, must be done through an official translation agency, which is a timely and costly investment. The question that is often asked is if this investment contributes to including more patients in clinical trials, and if it positively affects the study results. Second, translating PIFs and other forms to foreign languages other than Dutch and English is problematic as the researchers and research nurses do not understand what the patient fills in the questionnaire. Third, there is often confusion about the extent to which the PIFs can be simplified so that they still meet ethical requirements. The advisor for patient participation is critical towards these obstacles posed by medical professionals: “I do understand that it takes time, and it takes extra money, and it takes extra effort, I understand perfectly. [...] But I don’t think it’s justified, [...] for me that would not be an argument”.

### 3.2.2. Personal barriers

When asked to participate in medical research, patients may experience personal barriers, such as lack of trust in medical research or science in general, have privacy concerns, and fear potential side effects of the treatment. First, the medical professionals notice that patients experience some distrust towards medical studies and scientific research. Moreover, they find that patients who lack trust in scientific research or have privacy concerns in regards to what happens with their data once they participate tend to not take part in the clinical trials. This is in line with the study of Broekstra et al. on trust in data repository for human research, who state that “trust in [research institutions] is a key factor in determining individuals’ willingness to participate in epidemiological research and provide personal data to biobanks” (2019, p. 2). Such patient suspicion is exemplified by the doctor involved in the clinical trials. He tells us that some patients question what will happen to their data; will it be shared and with whom will it be shared, also how sure are the medicinal professionals that the data will be anonymized? As acknowledged by Sheridan et al. (2020), distrust in academic research is a common barrier to patient participation in clinical studies.

Secondly, patients who have experienced prior side effects to treatment in the past may be skeptical and fear the risks involved in taking part in another clinical trial. The type of study influences patients' fear. According to one of the research nurses, patients are especially reluctant to take part in randomized placebo-controlled<sup>3</sup> studies, because patients like to know if they are being treated and not given an inactive

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<sup>3</sup> The randomized placebo-controlled clinical trial is most often mentioned by the research participants, and revolves around a group of volunteers of whom a few are “randomly assigned – that is, selected by chance – to either a test group receiving the experimental intervention or a control group receiving a placebo or standard care. A placebo is an inactive substance that looks like the drug or treatment being tested.”

(Source: <https://www.nia.nih.gov/health/placebos-clinical-trials>)



substance to which they may have been blinded, otherwise, the investment of partaking in a study is too high. This is echoed by Patel et al. (2003), who see that patients are hesitant to partake in the study if the risks involved and outcome of the study are unknown: ‘will they be cured?’ or ‘will they [these studies] be blinded and [will patients be] given a placebo drug?’ This is in line with Hulley et al. (2013), who state that the possibility of receiving a placebo treatment is often a source of concern. The trust in clinical trials is then imperiled by fear of undesirable outcomes.

Aside from the aforementioned personal barriers, other personal considerations and motivations may also enhance, instead of impede, patient participation. Medical professionals acknowledge that when patients have an intrinsic motivation to participate in a medical study, they end up partaking. Sheridan et al. (2020) explain that the personal benefits, may it be the potency of being cured or a more altruistic motive to help cure other rheumatic patients or future rheumatic patients, are the most commonly reported factors to enhance patient participation in medical research. Such altruistic motives are exemplified in the following quote from a doctor-researcher:

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*[...] often, there are enough patients who are willing to participate without getting anything in return, they just do it for the greater good or to collect karma points, because they might have a family member who is seriously ill and they want to help them, so yeah. I find such altruistic motivations more important than money.*

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It can be questioned how a patient’s motivation to take part in clinical trials can be measured, and how much of that assessment is based on one’s own assumptions and biases about a specific patient’s desire to participate based on intrinsic motivation. We will later go into such assumption-driven barriers to including patients in rheumatic clinical studies; first, we discuss the relational barriers between the medical professionals and patients that influence patient participation.

### 3.2.3. Relational barriers

“It especially has to do with the relationship between doctor-patient. If there is a lot of trust, mutual trust, then the patient will more easily take you up on your advice”, says one rheumatologist. From this quote, it can be deduced that the relation between the physician and patient is of great importance to patient participation in clinical trials. The research nurse acknowledges this, in saying that if patients have a good relationship with their physician then the question “would you participate in this [clinical trial]?” would be more positively considered. There are however some barriers to this good relationship between medical professionals and patients.



Factors that play a role are the positionality of the physician; are they an authority figure? Here, age plays a role, as well as gender (e.g., male doctors are assumed to have more authority than female physicians). In addition, the official position/title of the medical professional, such as a physician, doctor-researcher, research nurse, or a doctor, could influence the willingness of patients to take part in clinical trials. This might be influenced by the position of medical staff in the hospital hierarchy, (i.e., the higher you are positioned, the more respect you receive), the interviewees see that this mostly has to do with time and the availability of the professional. The coordinator clinical trials explains this with the following anecdote:

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*[...], physicians are always busy and therefore are hard to reach. Patients are able to ask me something in between, for example, when I am walking with them to a different department. Then you notice that they loosen up. At the physician, patients know that they might get ten to fifteen minutes. This makes people nervous.*

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Taken from this quote, the lack of time for patient consultations of the different medical professionals in the busy hospitals may influence patients' relation with the medical professional, and ultimately could enhance the amount of trust that patients might have in partaking in clinical studies. This is echoed by the doctor, who sees that patients are more open to participating in clinical studies when there are many moments of contact between physicians and patients.

For the advisor for patient participation, feeling that medical professionals listen to you is crucial for patients to develop a good relationship with the professionals and it positively influences the participation of patients in clinical studies. The importance of a good relationship concerns all medical professionals and patients. Taken together, this section then shows how relational factors act as barriers as well as facilitators in impeding or increasing individuals' willingness to participate in clinical trials. Yet, many of these factors mentioned by medical professionals are assumption-driven.

#### 3.2.4. Assumption-driven barriers

Despite the notion that without patients there is no research, many patients are not able to partake in clinical trials, not necessarily because they do not meet the inclusion criteria or speak Dutch insufficiently, but just because the medical professionals in charge assume that they do not want to participate. The coordinator of clinical trials acknowledges that many physicians have prejudices and biases about the patients who are and those who are not willing to partake in clinical trials. A rheumatologist admits to his own prejudices and tells us: “beforehand, I try to figure out which patients would be willing to participate, so you are already



having some biases, you do have those”. Assumptions are based on a first impression, facial expressions, manners, appearance, and the overall vibe and gender.

First, the medical professionals may judge the likelihood of participation on someone’s appearance and ways of being during the first consultation. A first expression might be that a patient seems rushed, which according to the rheumatologist can mean that they do not have time for the consultation, and ultimately do not have time to partake in the trials. Patients then leave the consult without having been informed about a clinical study, despite meeting the criteria. Second, gender differences are an assumed barrier to patient participation in medical research. For instance, some consider women to have more time to participate in clinical trials because, unlike men, they less often have a full-time job (rheumatologist). As a consequence, women might be informed about the clinical trials taking place, whereas men might not be informed at all.

In the interviews, other assumptions were made about the patient population that may affect the individual motivation of patients to participate and the relation between doctor and patient. For instance, some medical professionals assume that the native Dutch population is more skeptical about scientific research in comparison to individuals of another nationality, impeding their participation in clinical trials. Also, some interviewees see that patients with a non-Dutch cultural background often have a lot more trust in physicians, who are considered authority figures. Medical professionals assume that individuals with a certain cultural background might then be more willing to partake in medical studies. The retired rheumatologist talks about the impact of culture on patient participation: “There are cultures where patients immediately say ‘yes’ when advised to partake in a study, but that is actually not what you should want to happen. You want the patient to actively think about the possibility of partaking in the trial themselves”. With the term culture the retired rheumatologist means how you have been raised, what you think, and how you behave, making this quite suggestive, subjective, and with that an assumption-driven statement. Some medical professionals thus have biases towards certain patients and these prejudices and assumptions influence patient participation in clinical trials. In result, there are more patients willing to participate than being asked to partake; hence there is a large group of patients who are not included in medical research.

### 3.3. Final reflections

In this chapter, we looked at patient participation in clinical trials in rheumatoid diseases, and provided insights into the challenges medical professionals face in engaging and recruiting a diverse group of patients in rheumatic clinical trials. Moreover, we identified the barriers that medical professionals think impede and increase individuals’ willingness to take part in these trials. We argue that practical barriers (e.g., hospital structures, workflow, and lack of time and money), personal and relational barriers (e.g., personal motivation and relations between doctor-patient), and assumption-driven barriers (e.g., personal biases of





medical professionals) impede or enhance patient participation in clinical trials. We emphasize that these barriers should be taken into account, and be critically reflected upon to engage a diverse mix of rheumatic patients in clinical trials. All of this is necessary as a diverse sample of patients is needed to test the effectiveness and safety of new drugs to alleviate or cure rheumatoid arthritis and to make the results more meaningful for real-world care and treatment. Simply put, to use a quote by the advisor for patient participation: “without patients, you have no research, no work, you have nothing, so just do something to include all patients”.

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## Chapter 4. The Workplace

This chapter concerns the domain of the workplace and focuses on the unheard and unseen group of Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex (LGBTQI+) employees. This group of LGBTQI+ employees continues to face discrimination at work (see McFadden, 2015; Priola, et al., 2018; Van der Toorn, 2019). However, due to the concealability of their identity and the fact that many remain closeted at work, their voices are not heard, or are even silenced (McFadden & Crowley-Henry, 2017). Moreover, albeit being one of the largest minority groups in organizations, LGBTQI+ employees are the least studied group in the workplace (Ragins, 2004; Ragins et al., 2007; Ozturk & Tatli, 2015). In addition, the diversity of identities encompassed by the LGBTQI+ acronym appears to not be fully considered by researchers and other professionals (Ng & Rubens, 2017). For instance, the 2018 Dutch LGBT Monitor shows that surveys often ask LGB individuals about their identity but refrain from assessing TQI+ identities, “resulting in lack of insight on the positioning of transgender individuals and individuals with an intersex condition” (Van Beusekom & Kuyper, 2018, p. 11). Besides that, the intersecting identities of employees (e.g., being male, gay, and black) and their interplay are understudied (Dennissen, 2020; Thomas et al., 2021). An intersectional lens can, however, be used to understand the power struggles through which inequalities in organizations are (re)produced; that is beneficial to the development of diversity policies of organizations. A first step then would be to acknowledge that there are employees with intersecting identities and attempt to address their possibly specific needs.

In this chapter, we explore a) the strategies Human Resource (HR) and Diversity and Inclusion (D&I) professionals use to assess the needs of LGBTQI+ employees, and b) whether and to what extent these strategies are likely to reach LGBTQI+ employees with intersecting identities. In doing so, this study draws on the diversity and inclusion management practices employed in the workplace domain and academic studies exploring the concepts of diversity and inclusion. While these concepts are related, they are not the same. Diversity regards the composition of groups or workforces, and refers to relatively observable differences in terms of gender, race, ethnicity, age, physical (dis)abilities, and non-observable differences,



including cultural, cognitive, and technical differences amongst employees (Roberson, 2006). Inclusion, as Jansen et al. propose, “is a hierarchical two-dimensional concept consisting of perceptions of belonging and authenticity” (2014, p. 381). On the one hand, belongingness relates to the extent an individual feels attached to a group. On the other hand, authenticity points towards the uniqueness of individuals and their differences (Jansen et al., 2014). Thus, a diverse team does not guarantee that the organization is inclusive. Likewise, an inclusive workplace does take all differences and intersecting identities of employees into account. We see that the discourse is increasingly shifting to one of inclusion, “over and beyond that of diversity” (Nair & Vohra, 2015, p. 4).

The findings presented in this chapter are based on a review of the literature on current diversity and inclusion management practices and LGBTQI+ employees’ experiences at work. Furthermore, we conducted thirteen in-depth interviews with different HR managers and consultants, D&I officers, a manager of Inclusion and Social Entrepreneurship, a representative of an intersectional interest group, and chairs and board members of the LGBTQI+ networks in the respective Dutch organizations. These interviewees varied in age, gender, sexual orientation, organization-type, and profession. The organizations were either mid-sized organizations with up to 250 employees, or large organizations with more than 5000 employees. First, this chapter examines the different strategies employed by the interviewees to assess the needs of LGBTQI+ employees. We explore the degree to which these strategies are proactive versus reactive in nature and the likelihood that they succeed in reaching all LGBTQI+ employees. Second, we provide an overview of the different barriers we identified in the professionals’ attempts to assess the needs of LGBTQI+ employees.

#### **4.1. Strategies to assess the needs of LGBTQI+ employees**

The organizations undertake a lot of activities in their attempt to create a more inclusive work climate, yet strategies specifically aimed at uncovering the needs of LGBTQI+ employees are relatively sparse. Such activities are training and mentoring programs (e.g., effective leadership programs), promotional campaigns, official complaint procedures (e.g., the complaints box and a counselor), the employee networks, and short-term pilot projects (e.g., D&I quizzes amongst employees). Quite a few of these activities are reactive (‘come find us’), such as the complaints box, but there were some that had the potential to be proactive (‘we will reach out to you’). We discuss three proactive strategies used by professionals to assess the needs of LGBTQI+ employees, which are promising if employed correctly: the employee satisfaction survey, the LGBTQI+ employee networks, and dialogue and stories.



### 4.1.1. The employee satisfaction survey

An employee satisfaction survey is a tool that organizations can use to assess the job-related attitudes and experiences of their employees, including their job satisfaction and sense of inclusion and well-being. As such, they provide insights into the health of the organization and its employees. The surveys may also contain questions about the personal characteristics of employees, such as their gender, age, sexual orientation, and gender identity. These questions help organizations in identifying group-based inequalities and forming targeted interventions towards combating these inequalities (Van der Toorn et al., 2021). The survey can, for example, be utilized to determine if certain employee groups such as those with different intersecting identities feel less included at work and if so, implement inclusion initiatives to reduce this gap. The D&I manager we interviewed finds the employee satisfaction survey a great method to ask standardized questions about the well-being of employees. Her organization is additionally using a Pulse Survey, which is similar to the employee satisfaction survey but shorter in length, more specific in topic, and sent out at more frequent intervals. The HR consultant compares the Pulse Survey results on group specific experiences to the more general results from the employee satisfaction survey. The Pulse Survey can be used to assess why certain employee groups might feel more left out than others, and what actually causes this difference in experience. Thus, in addition to the employee satisfaction survey, the Pulse Survey offers a deep dive into specific issues, questions, and the different experiences of employees. In theory, then, the employee satisfaction survey (and derivatives like the Pulse Survey) constitutes a rather proactive strategy, as it involves an assessment of the lived realities in the workplace, which can inform policy development and implementation.

Most of our interviewees, however, did not seem to use the full potential of the employee satisfaction surveys, as they only included general questions and did not assess employee group memberships. The manager of Inclusive and Social Entrepreneurship uses the surveys to ask general questions, “we just ask about whether they [the employees] are still happy with [name organization], that sort of thing”, whereas topic-specific or group-specific questions might be needed to engage in difficult conversations and facilitate change. Furthermore, even among the professionals whose organization did assess group membership and ask diversity and inclusion related survey questions, most did not have a clear plan in place for what to do with the results. Other professionals indicate that their organizations want to use the survey to cover other topics; questions about diversity and inclusion, and specifically sexual orientation and gender identity are not prioritized. The Senior Consultant I&D wonders whether organizations are allowed to ask for such private information, and struggles with the fine line between obtaining personal information and breaching someone’s privacy. Yet, according to the HR consultant, such concerns are just excuses to avoid asking difficult questions.



As Van der Toorn et al. indicate, the collection of data on employees' sexual and gender identities creates new challenges, as it requires individuals to 'out' themselves, and this "is a more precarious issue for sexual and gender minorities than it is for the majority" (2021, p. 54). And even when the information is collected anonymously, LGBTQI+ employees might not answer truthfully out of fear that it might not be entirely anonymous. To provide their sexual orientation and gender identity in workplace surveys, employees need to have a lot of trust in the process and in the professionals who work with their data. This is echoed in our interviews, in which the professionals tell us that employees may be reluctant to share this information. Professionals themselves also seem reluctant; they fear that asking questions about employees' personal characteristics may violate their privacy. Few professionals, however, ask their employees how they would feel about such data collection, and the one D&I manager who did, decided against asking questions about employees' cultural background, sexual orientation, and gender identity despite receiving limited feedback from employees. As a reason, they noted the possibility that people would rather not answer those types of questions.

Another issue with the execution of the employee satisfaction survey is that identity intersections are not examined (e.g., between sexual orientation and ethnicity), and thus cannot be taken into account. The representative of the intersectional interest group regrets this because employee satisfaction surveys can be a good tool to assess employee needs if they do not just concentrate on a few aspects of a person's identity, but take into account multiple categories of difference that constitute a person's identity. He says:

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*Then you may have data that the management can use to say something about what is happening in the workplace, but the data does not represent me. It is about me as an LGBT person, but not about me identifying as LGBT in relation to my blackness. While my LGBT identity is often determined in relation to my blackness.*

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As the representative of the intersectional group indicates, he is first and foremost seen as black, and his LGBTQI+ identity is overlooked. If the surveys do not contain questions that assess employees' intersectional identities, some individuals will be left unseen and voiceless. We argue that intersecting differences of individuals should be taken into account in the employee satisfaction surveys to represent all individuals in the organization and get an understanding of what is happening in the workplace. In this way, an intersectional lens is beneficial to the development of diversity policies of organizations, and ultimately will enhance the well-being of employees. Hence, even though some organizations refrain from questioning about employees' sexual orientation, gender identity, and other intersecting identities, the employee satisfaction survey, if done correctly, is a good first step to learn about group-based inequalities and help counter these. Now, we turn to the second strategy: the LGBTQI+ employee networks.





### 4.1.2. The LGBTQI+ employee networks

The LGBTQI+ (diversity) networks, also known as employee resource groups (ERGs), affinity groups, or business resource groups, are another strategy in the diversity and inclusion toolbox of organizations. The networks are either formed by the actions of unions, by the companies, or by employees themselves, and aim to promote a welcoming environment to inform, support, and advance minority or underrepresented groups in the organization (e.g., women, LGBTQI+ employees, employees of color, youth, and employees with disabilities) (see Friedman, 1996; Foldy, 2002; Friedman & Craig, 2004; Derven, 2014; Dennissen et al., 2018; Dennissen, 2020). According to the Senior Consultant I&D, diversity employee networks are a formal mechanism that signal that organizations are consciously engaged in and attach meaning and importance to their diversity agenda.

The chairs and board members of the different LGBTQI+ networks and the representative of the intersectional interest group point out that the networks help improve the visibility of LGBTQI+ employees. The networks give voice to LGBTQI+ employees, and enable upward career opportunities by offering a safe space<sup>4</sup> for LGBTQI+ employees. The networks also organize events and are vigilant and critical about current diversity policies. The HR- and D&I managers we interviewed appeared to perceive the LGBTQI+ network as the main channel through which to reach the organization's LGBTQI+ employees, and thus a powerful strategy for assessing their needs. Most interviewees had periodic meetings set up for dialogue and exchange. The networks then functioned as an individual and collective voice mechanism, providing visibility and community for members, and promoting change (Colgan & McKearney, 2012; Dennissen, 2020; Meral & Van der Toorn, 2021). Network groups, then, “–if understood, supported and run well – may provide organizations with a powerful way to reshape the social environment for minority employees” (Friedman & Craig, 2004, p. 794). Our study shows that LGBTQI+ networks are integral to the diversity agenda of organizations and contribute to the mobilization of social change in the organizations as they provide insight into what is happening in the workplace and are able to push for open dialogue and debate on issues that arise. According to the D&I manager, networks provide the organization stories and sometimes a counternarrative to the dominant narrative shared in the organization. They point out the blind spots, tell us more than statistics, and shed light on what is really going on. Also, as mentioned by the HR manager, networks enable individuals to be role models advocating for change.

However, the chair of the LGBTQI+ network indicates that the networks should not merely be a tool for the diversity and inclusion office of an organization (especially if there is no clear diversity policy), but

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<sup>4</sup> Safe spaces are physical and metaphorical, referring to spaces where voices from the position of differences can be heard, usually of marginalized identities, to feel free of judgment or harm.



should challenge the organization and contribute to policy changes. This is proven to be not an easy feat in practice, as some network representatives tell us that they stumble upon barriers when trying to get new initiatives approved, such as the ‘gaybra’ (rainbow-colored pedestrian crossing) proposed by the board member of the LGBTQI+ network. Some members of the LGBTQI+ networks seem skeptical about their ideas being implemented, or about the extent to which they can bring about concrete organizational change. This is echoed by Foldy (2002), who sees that diversity networks often lack the power to challenge the status quo in organizations. The effectiveness of the network in bringing about actual change in the social environment of LGBTQI+ employees can thus be questioned. This skepticism may signal a certain distrust in organizations’ diversity management. It should be noted that the chair member of the LGBTQI+ network was doubtful about (and to a certain extent unaware of) the strategies in place, despite the D&I manager’ efforts. Future studies can explore the concept of trust in relation to employees’ perceptions of their organization’s diversity management efforts.

The networks do not include all LGBTQI+ employees as members, and may not be representative of the diversity among the organization's LGBTQI+ population. The HR manager finds that the networks are not a good representation of their constituent groups in the organization: “Where are the people of color, and where are all other people with different identity markers?”. Research shows that LGBTQI+ networks lack both gender and sexual diversity, and that reports of outreach programs to improve the diversity of the network members are rare (Finarsdóttir et al. 2020). Women – especially those with a bisexual or transgender identity – tend to be less visible in organizations

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*Yes, then I am talking about man-woman, because for a long time we only had two men on the board and we noticed that the number of female members were decreasing. And then we looked and said, ‘hey, we want more women on our board because we want to make sure that women also feel heard and safe in our network’. So, yeah, in that way it is important.*

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and LGBTQI+ networks alike (Dennissen, 2020). This is exemplified by the chair of the LGBTQI+ network in the following excerpt:

In line with this excerpt, the representative of the intersectional interest groups tells us that individuals with intersecting identities are often not represented in diversity employee networks, for that reason the intersection interest group was born, representing for instance LGBTQI+ people of color.

Even though the board members of the networks see that the networks fail to represent all LGBTQI+ employees of an organization, they acknowledge that they cannot refuse people that conform to the norm to become board members. We should note that the representativeness of the networks is then not just a depiction of the dominant norm – that of being a white, gay male – but is formed in organizations with a



specific demographic profile or put against the notion that the networks are welcoming to all LGBTQI+ employees and their allies. This is jokingly exemplified by the board member of the LGBTQI+ network of the university: “No, we don’t want you, because you are yet again another white male [laughs], no we have enough people like you, bye!” In light of this, the HR consultant believes that you need to continually ask what is wrong, and make sure that minorities are represented in the networks, in order to restore balance.

The representative of the intersectional interest group is vocal about the importance of LGBTQI+ networks having to address intersectional identities and work intersectionally. Such an intersectional lens is important to employ as intersectionality plays a large role in LGBTQI+ status inequality, and ways to challenge this. As indicated by Cech & Rothwell, intersectionality “underscores the importance of investigating ways LGBT status may moderate the gender and race workplace inequalities documented in prior scholarship” (2019, p. 27). Notwithstanding, we note that the LGBTQI+ networks a part of this study prefer focusing on a single identity category rather than having a broad focus. The networks see the importance of separate networks to safeguard the safe space that the networks can offer and continue to address group-specific issues. However, in doing this, the board members of the LGBTQI+ network of the university find that there is a danger that the networks become isolated, losing sight of other networks and employees.

Nevertheless, all representatives of the LGBTQI+ networks are trying to work more intersectionally. For example, the chair of the LGBTQI+ network argues that organizing joint events with other diversity networks is a next step in becoming more inclusive for all employees. In rethinking and reworking the representativeness of the networks, Dennissen notes that “diversity networks can open up discussions about intersectionality, intersectional marginalization, and privilege” (2020, p. 133). The LGBTQI+ networks can then be vigilant and critical about current diversity and inclusion policy, and push for open debate to generate a better social environment for all employees. With the limitations of the LGBTQI+ networks in mind, we state that the LGBTQI+ networks can be a proactive strategy to assess the needs of LGBTQI+ employees and give them a voice. This is however only the case, if they remain reflexive about their own workings and that of the organization, and aware of problems that may arise. This brings us to the last strategy we discuss: the use of dialogue and stories to assess the needs of LGBTQI+ employees.

### 4.1.3. Dialogue and stories

A third strategy to assess the needs of LGBTQI+ employees in organizations revolves around dialogue and stories. Dialogue as a tool of diversity management is twofold. First, dialogue can initiate open debate on biases and blind spots in regards to LGBTQI+ issues and rights, as explained by the board member of the LGBTQI+ network of the university. Second, it can facilitate a conversation with both the minority and dominant group to foster inclusion and bring about change. As the HR consultant explains, it is all about



having uncomfortable conversations with the respective ‘other’ – someone from the minority or majority group – by asking the difficult questions, “what is diversity to you?” “What does it mean to be inclusive?” The chair of the LGBTQI+ network uses playful conversational tactics to start the conversation. For example, when someone would say: “I’m totally okay with you being a lesbian”, then she would respond by saying, “I’m also totally okay with you being straight”. Through this playful intervention, normative discourses are criticized while at the same time processes of normalization take place as queerness is legitimized. As the HR manager says, it is all about “biting the bullet”, because then you are able to see and understand the perspective from someone else’s point of view. For the HR manager, perspective is key, because ultimately it is all about seeing and treating each other as human beings, on equal footing, without biases, and understand that you each have something to offer the other. She says, “love is the basis of it all, love for one another, that you wish the other something and that you are not opponents, but embrace each talent”. These findings show that engaging in such intergroup dialogue and using multiple perspectives are important to facilitate an inclusive workplace, as echoed by Ferdman et al. (2017).

Dialogue can also be a means to collect and listen to the stories containing the experiences of the employees, which is another interesting tool mentioned by the D&I manager. She explains that narratives are crucial; they are the stories behind the statistics that tell us about what is going on in the organization. Stories then may emphasize the urgency for change. Such narratives need to be brought to the forefront of the discussion in the organization so that adequate action can be taken. The D&I manager also indicates that after hearing someone’s story, changes should be communicated in the organization, so all employees are aware of what is going on and know that respect is needed. In this way, stories representing (invisible) LGBTQI+ employees are utilized to generate a change in the social environment of the organization, and are a tool to provide these employees with a voice to speak out and share their personal experiences and express their needs.

When the management is open to feedback and communicates changes with their employees, the workplace becomes a place where there is room for diversity and where inclusion can be fostered. By listening to and collecting stories, the D&I manager provides unheard and unseen employees with a voice. Taken together, dialogue and collecting stories are proactive strategies and powerful tools to assess and advocate for LGBTQI+ employees’ needs and to engender a change in the social environment for these employees. It should be said that despite the efforts of professionals, some representatives of the LGBTQI+ networks noticed little of their efforts. Also, many LGBTQI+ employees remain unheard and unseen in the workplace due to different barriers, which we will explain now.



## 4.2. Barriers to assessing the needs of LGBTQI+ employees

### 4.2.1. Practical barriers

From our interviewees multiple barriers can be identified that impede the efforts of professionals in assessing the needs of LGBTQI+ employees in organizations, namely practical, socio-cultural, and assumption-driven barriers. We first discuss the practical barriers. Firstly, the hierarchical structures in the workplace are considered a barrier. Even if diversity managers do their utmost best, their ability to bring about change is limited due to power structures and managerial restrictions in organizations. Some interviewees admit that they run into a wall of bureaucracy, because there is limited support from the executive board for implementing changes. The HR manager explains: “At one point, a question was raised [by an employee] like ‘can we get gender-neutral toilets at the head office?’ I said ‘yes, I can propose that’, but you notice that there is very little support for realizing that”. This example shows that HR and D&I managers (sometimes) have limited ability to inflict change in organizations. Another example of this practical barrier is the absence of formal diversity policies, as indicated by the HR manager. According to the Senior Consultant I&D, having formal diversity management executed by the executive board of an organization is crucial, so that “the tone is set at the top [...] – with the people who ultimately make the decisions and can initiate formal changes”.

Secondly, organizations often lack labor force and time as a result of a small or in some cases non-existent D&I budget. Hence, diversity and inclusion work comes second to other work-related tasks. That this is a barrier that hinders change is emphasized by the university’s HR policy advisor. Although she is critical towards diversity management which focuses on simply ticking boxes to meet the requirements, she admits that the university is forced to this “because we are just too busy, [...] I’m just telling you honestly”. Thirdly, another practical barrier concerns the complicated internal and external ICT systems. Some interviewees describe the difficulties they encounter in changing the binary gender categories (male and female) to more diverse categories in the personnel system. Moreover, not including questions about one’s gender identity and sexual orientation in the employee satisfaction survey is often blamed on to the complicated external ICT systems. Some organizations outsource the surveys to external companies, which makes it difficult to change the surveys as the systems used are beyond the control of the organizations themselves. Although this might just be another excuse to not pursue changes in the organizational processes and functions, as the HR consultant indicates, it is important to take note that these practical barriers impede efforts in reaching LGBTQI+ employees and the work done to mobilize change for these employees at work.



#### 4.2.2. Socio-cultural barriers

This study demonstrates various socio-cultural barriers that are embedded in Dutch (organizational) structures. First, the normalization of discriminative remarks as accepted human behavior. Today, LGBTQI+ employees face a wide range of discriminatory acts which range from overt to more covert; also known as microaggressions (Nadal, 2018; Rivera et al., 2012). The HR policy advisor and board members of the LGBTQI+ network of the university consider such microaggressions a part of everyday life at work. They feel that LGBTQI+ employees may need to expect and accept that discriminatory remarks are bound to happen in the workplace. Knowing that one might have to endure such discrimination when coming out may cause them to stay closeted and remain invisible to the professionals trying to reach out to them. They might not participate in focus groups on D&I or complete a survey.

Second, heteronormativity continues to pervade Dutch organizational discourses. According to Reingardé, “[the] heteronormative discourse acts as a mechanism of power and control that limits the ability of gay and lesbian people to talk and construct their own identities at work” (2010, p. 85). Particularly in the workplace, as Mizzi (2013) points out, through adhering to the heteronormative discourse (e.g., being heterosexual or acting according to the heterosexual norm), a person gains respect and power in the organization. Mizzi refers to this process as heteroprofessionalism, making heterosexuality the norm which may silence the sexuality of employees. As a result of this persistent discourse, LGBTQI+ employees may experience fear of coming ‘out’ due to possible backlash, and feel pressured to be silent (Reingardé, 2010). The D&I manager provides us with an anecdotal example of the heteronormative culture at work and the difficulties this poses for LGBTQI+ employees:

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*Recently I spoke to a man, an engineer, who came out at the age of sixty. He said, ‘no, everyone is very relaxed about it, I don’t experience any negativity’. But yes, that is just one team right. It could be very different in Friesland in comparison to the Achterhoek or Amsterdam. Even though you can think that the Amsterdam branch is gay-friendly, but there you can also be placed in a team with macho men who bully you. So I think that there are many cases where individuals stay closeted.*

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This quote highlights, as McFadden and Crowley-Henry argue, that the heteronormative climate within organizations can silence the voices of LGBTQI+ employees due to “stigmatization, discrimination, and the fear of negative career-related consequences” (2017, p. 1077). Thus, the normalization of discriminative remarks which are fed by the heteronormative discourse pose an obstacle to reaching LGBTQI+ employees and limit their voice to help shape – what is often called – an LGBTQI+ friendly workplace.



### 4.2.3. Assumption-driven barriers

Last, we found that many of the barriers to reaching invisible LGBTQI+ employees are assumption-driven. For instance, the HR manager tells us that a formal diversity policy is not needed because all is good in the organization. Although LGBTQI+ issues are said to be of little concern in the organization, the HR manager acknowledges that there is discrimination, and “it’s not as rosy as you would think, ‘with us everything is fantastic and everyone is accepted’”. This remark is not only contradictory, but also suggests a lack of critical reflection and builds on an assumption that all must be in order. However, once thought over, all is actually not well.

There are also assumptions about LGBTQI+ employees who do not participate in the network. According to the Senior Consultant I&D, some LGBTQI+ employees might either not join the network (yet) because they are still closeted or in the process of coming out, or because they do not need the network as they are openly out and encounter no issues. The Senior Consultant I&D also finds that it is difficult to reach out to LGBTQI+ employees who remain closeted or who struggle with coming out themselves. Moreover, the chair of the LGBTQI+ network states that there are LGBTQI+ employees who might be reluctant to join the network for fear of backlash, such as discriminatory remarks after ‘outing’ themselves. In their study on joining and participating in employee networks, Friedman and Craig (2004) similarly denote this fear of discrimination. None of our interviewees noted the possibility that LGBTQI+ employees might not join the network because they do not feel represented by it (e.g., due to their intersectional identities), or because they do not agree with its approach or objectives. Hence, assumptions may prevent networks and diversity managers from reaching out to all LGBTQI+ employees, and could impede the possibility of giving all LGBTQI+ employees a voice and advocate for their rights, and to eventually bring about systemic cultural change at work.

### 4.3. Final reflections

This study drew upon diversity management strategies aimed at better representing and including invisible LGBTQI+ employees in organizations, and provided insights in some of the challenges in reaching these employees. Of the strategies organizations use to assess LGBTQI+ employee needs, we identified three that are promising if implemented correctly: (1) the employee satisfaction survey, (2) the networks themselves, and, (3) dialogue and stories. We see that the professionals implemented these strategies in varying degrees and acknowledge that the effectiveness of the strategies used depend on its full implementation (and the way it is received). We also identified three barriers in reaching invisible LGBTQI+ employees. These barriers are (1) practical (e.g., lack of time, money, and labor force, and technical complexities), (2) socio-cultural (e.g., the normalization of discriminative remarks and a persistent



heteronormative discourse), and (3) assumption-driven (e.g., LGBTQI+ employees might not join the network because they are already comfortable in their own skin, so why would we reach out to them?). It is important to note that these barriers are never singular; they overlap and influence each other. Critical reflection of the different barriers and strategies used is then needed in order for all LGBTQI+ employees to be reached, supported, and engaged with in the organizational context.

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## Chapter 5. The Neighborhood

Despite continuous efforts, professionals often fail to engage certain groups of residents in neighborhood projects and activities aimed at supporting and engaging citizens in society (Dibi, 2020; Uytterlinde et al., 2020). Dibi states that this could be problematic as “residents who are not reached could become estranged from society, which may result in bigger problems” (2020, p. 4). Over the last decades, broad trends have influenced and restructured European welfare states, which has large implications for the government of society and its citizens (Hurenkamp et al., 2011). As a result of Dutch welfare state retrenchment, new forms of ‘active’ citizenship have been encouraged, requiring citizens to take ownership, responsibility, and to be *zelfredzaam* (best translated as self-reliant) of their lives and the challenges they face rather than relying on governmental services (Tonkens et al., 2013; Bredewold et al., 2019; Fenger & Broekema, 2019; Grootegoed & van Dijk, 2012; Ubels, 2020).

Within this new participation society, social professionals are assigned an important role, in which “it is their task to assess citizens’ care needs and to determine to what extent family and other social network members can provide help” (Bredewold et al., 2019, p. 763). However, as emphasized by Dibi (2020), professionals in the neighborhood experience difficulties in reaching out to and engaging individuals in their projects. Moreover, the shift to self-reliance has implications for many neighborhood residents, especially those in vulnerable positions, as they often do not have the capacity to be (fully) self-reliant (ibid.). As a result, neighborhood residents may feel reluctant to reach out to professionals and their projects. The surrender of public responsibility by the government widens the gap between individuals and society and results in people hiding their problems (Grootegoed & van Dijk, 2012), which may cause large groups of individuals in society to be overlooked.

To address difficulties in involving individuals in neighborhood activities and projects, a better understanding of how professionals in Dutch neighborhoods reach out to, engage with, and support individuals that are not seen and heard is needed. This study aims to outline the strategies that are used by



professionals in a city in the Netherlands to reach (invisible) individuals in the neighborhood. We conducted in-depth interviews with eight different neighborhood professionals who work towards involving individuals in neighborhood activities aimed at improving neighborhoods. We talked to researchers involved in different neighborhood projects, two representatives of the municipality, coordinators and representatives of social organizations, and a local church support in the neighborhood. Some interviews took place online; others in the offices of the organizations.

This subchapter considers the definition of the neighborhood and highlights the complexity of the social navigation of residents that may hinder them from reaching or being reached by professionals. We further identify different strategies and approaches that are used to engage individuals in the neighborhood in projects and discuss barriers that make it difficult to reach invisible individuals, pointing towards practical, socio-cultural, and assumption-driven barriers. We end by critically reflecting on the strategies used by professionals to reach and engage certain groups of individuals in neighborhood projects, and ultimately in society.

## 5.1. Conceptualizing and navigating the neighborhood

There are two main approaches to defining the neighborhood. As Jenks and Dempsey (2007) describe, first, the neighborhood is seen as a spatial and functional construct defined by the physical features that bound it, in which people live and have a community. Second, the neighborhood is seen as a social construct defined by administrative boundaries imbued with meaning given by the people who live there. In line with these two definitions, some of our interviewees talk about the neighborhood as a space where people come together, a space for community, or mention the formal construction of the neighborhood. Others see the importance of understanding how people in the neighborhood demarcate social space, how they navigate the formal borders, and where they draw the line between one's social space and the other. The local church support finds it is most useful to understand how neighborhood residents define social space and see who they believe are a part of that space and who belong somewhere else.

The perspective of neighborhood residents in defining social space is again mentioned in conversation with the sports broker, who indicates that there are physical and mental borders to a neighborhood. She tells us that for many residents (especially those in vulnerable positions) social spaces are defined by their physical borders, yet it is the mental borders that limit the way residents navigate social space<sup>5</sup>. Such mental borders might be the distance, lack of knowledge about the adjacent neighborhood, and fear of the unknown. These

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<sup>5</sup> Social navigation concerns how flows of people move in a space, as it influences where we stand or go from there, and can be used to look at social mobility and agency in the neighborhoods and their residents (Vigh, 2009).



borders do not just delineate the way neighborhood residents navigate (social) spaces, but show that spatial borders are imbued with social meaning that shape the relationship people have with a space. Both the literal and social borders should be considered as potential barriers to the efforts of professionals to engage residents in their projects and activities, as they might literally be located too far from the neighborhood the residents live in or require them to cross-over social boundaries. In this way, the way the neighborhood is defined and socially constructed needs to be kept in mind as we discuss the different strategies different professionals use to improve the social environment and livelihood of neighborhood residents.

## **5.2. Strategies towards involving residents in neighborhood projects**

### **5.2.1. Reactive strategies: From information resources to self-reliance**

Strategies of professionals to involve residents in neighborhood projects vary from more reactive strategies ('they should come and find us') to proactive strategies ('we will find them'). First, we focus on the reactive approaches. Getting residents to apply for financial funding at the different associations and organizations is a reactive process because the initiative of applying lies with the residents themselves. The children's sports fund and the children's schooling fund both offer financial support to children with a city pass; these are children whose parents have a monthly income up to around 1800 euros. Despite the fact that parents can apply for financial support for their child for free, they need to apply themselves. According to two researchers working on a neighborhood project, this self-application process is quite bureaucratic and not everyone may know how to work through the paperwork involved. As a result, many residents have not been reached.

Another more reactive strategy to support neighborhood residents and engage them in projects and activities concerns the resources organizations use to inform residents about their organization, projects, and activities. They make use of flyers, posters, social media, and a personal website. One of the researchers of the neighborhood project tells us that they work with flyers, posters, or Instagram: "so [we make] use of visual material aimed to communicate specifically with girls to engage them in different sports activities". For the sports broker promoting with flyers might not be enough, instead they use their entire network to make children enthusiastic about sports and to inform children about the possibility of applying for financial support for sports activities and clothes through the fund. Mouth-to-mouth promotion is then key to getting more residents involved in the projects.



It should be noted that these reactive strategies are embedded in the Dutch political climate that encourages active citizenship and self-reliance. It is not surprising that some of our interviewees indicate that certain residents in the neighborhood find help in their personal circle, e.g., family members, friends, or acquaintances. According to the local church support, informal networks are key to building trust with residents and a solution to communicate with residents with a language barrier. The importance of informal networks in supporting neighborhood residents is in line with the shift in responsibility of social welfare by the government as citizens are now expected to find care arrangements within their own networks (Grootegoed & van Dijk, 2012). Such self-reliance can be seen in the following excerpt from the interview with the coordinator of the children's schooling fund, who sees that residents help each other in coping with their problems:

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*From [name neighborhood] we rarely get any requests, on occasion the bare minimum is asked for, while there is a large group of individuals who are living in poverty. Yet, they solve their problems by relying on their neighbors. This is great, I believe in this. [...]. What I like is (...), I know a story about a neighborhood nurse working in [name neighborhood]. They told me that if one person could not pay for their needs then someone else would do so. If that person had problems, for example if they could not pay their bills, then someone else would help them with that. The neighbors were relying on each other.*

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From this quote, it can be deduced that it may not always be a problem if residents are not reached and involved in neighborhood projects as they rely on each other. However, due to great self-reliance of citizens, there is a possibility of residents becoming isolated and alienated from society, which could ultimately impede their participation in society. Also, some residents might struggle to be self-reliant. Or as Broeders et al. (2018) say, neighborhood residents might be overestimated in their capability to make healthy lifestyle choices and to stick to them. It is great that residents are able to support themselves or rely on one another, but it might not be enough to help solve their problems or support their needs. The following section explores the proactive approaches used by our interviewees in reaching neighborhood residents.

### **5.2.2. Proactive strategies: Being present and the inner perspective of neighborhood residents**

Aside from these more reactive strategies in involving residents in neighborhood projects, we find that most strategies mentioned by the participants in this study are proactive. The strategies explored in this section are the following: (1) house visits by the children's schooling fund, (2) neighborhood sports coaches



facilitating dialog with children and their parents in different neighborhoods, and (3) the presence approach used by the local church support. All strategies involve direct contact with neighborhood residents and active engagement of professionals in the neighborhoods. Further, the strategies all focus on the inner perspective of neighborhood residents, aimed at the underlying question: ‘what do the residents want and need?’

A proactive approach to reaching and engaging residents in neighborhood projects is the house visits undertaken by the children’s schooling fund. The financial schooling fund works with a number of volunteers. After having received an application for funding, one of the volunteers goes to the house of the applicant to talk about why they are applying for funding and what the overall financial situation is like. At times, volunteers notice that families need more than just financial support for the schooling of their children. If this is the case, the fund tries to support the family as best as they can or ask a partner organization to help out. The coordinator of the children’s schooling fund provides an example of this:

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*During one house visit a volunteer was sitting on the only chair in the house; the rest [of the family] were sitting on mattresses, their floor was bare. The family had just moved after the mother passed away and the father had a hard time because of this. Moving houses was done as efficiently as possible, but the father struggled to open all the boxes; there were too many memories and he experienced psychological barriers in opening them. Our volunteer noticed this. I spoke with her to see if we could find a buddy to help the family. We did.*

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In offering more support than what is asked for (e.g., financial support for the schooling of children and related activities), the organization aims to bring about sustainable change. Yet, as neighborhood residents have to take the first step by applying for funding themselves, many families in need will literally remain invisible to professionals. Nevertheless, the house visits are an example of a proactive strategy employed by the organization to assess the needs of residents, figure out what the problems are, and offer support.

Another proactive strategy mentioned in the interviews is having dialogue with neighborhood residents to inform them about the support that can be offered. The importance of dialogue was talked about by the sports broker. She says, “we often try to have conversations and make [children] enthusiastic about sports, so that children or parents will say ‘yeah, that might be really nice’”. There are sports coaches in the different neighborhoods; they organize activities, such as street sport (for free), and provide activities for children at after-school care clubs. In doing so, they work closely with the schools. It is key that the activity aligns with the needs of the children. In order to do so, the sports broker tell us that sport coaches ask questions such as: “what do you like?” and “what do you want to do?”. By actively trying to engage children





in sport by asking what they want and need, the sports coaches use dialogue as a proactive strategy to engage children in sports activities in the neighborhood.

The final proactive strategy taken from the interviews is the presence approach<sup>6</sup> mentioned by the local church support. This method concerns three phases. The first phase is exposure and involves walking around a specific neighborhood without prejudices, writing about what you see, and reflecting upon these findings. The second phase is the contact phase (in Dutch the *straat-ontmoetingsfase*). In this phase, the professional approaches neighborhood residents, seeks connection, and builds a network. In doing so, it is important to place emphasis on understanding the inner perspective of neighborhood residents as the local church support indicates:

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*We are more focused on the everyday experiences and the inner perspectives of residents on the neighborhood; not about what you hear about the neighborhood from external sources (e.g., in municipal statistics and archives, newspapers, or what you hear from colleagues: 'oh, it is so bad over there', 'it is such a problematic area').*

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After this contact phase, the last phase concerns persistent contact between neighborhood residents and the local church support. This is necessary to build trust. The local church support points to the success of the method as some residents have expressed the importance of having talked to someone about concerns and struggles; they felt heard. Some, who otherwise would have stayed more hidden from working professionals in the neighborhood, brought the local church support into their home and shared about their multifaceted problems.

The two representatives of the municipality acknowledge how fruitful the presence method can be in the neighborhood context. One of their colleagues has been visiting homeless individuals on a daily or weekly basis in the city. Although we cannot be sure that she employs all steps of the presence method, it is clear that elements of the method are key in her work. The colleague continuously approaches homeless individuals, without biases, reflects upon her own behavior, and does not place herself on a pedestal – as someone better and higher than those she is working with –, instead she values equal human interactions. Here, the question ‘how do you want to be treated?’ is key. Also, the colleague takes into account the wants and needs of the homeless individuals. The success of this approach is reflected in the positive feedback and the unfolding conversations between the professional and the homeless individuals.

Together, the three aforementioned strategies outlined are proactive strategies that are employed to engage residents in neighborhood projects. Key to the success of the methods is a change in perspective of

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<sup>6</sup> For more information on this method, see the website of Movisie or see the document about this method on the website of Handjehelpen.



professionals working in the neighborhood. As the representatives of the municipality explain, it is not about what we can do for the target group, but what they want or need from us. The question is then, ‘how can we support?’ In doing so, professionals are able to employ the inner perspective of neighborhood residents to understand where support is needed, what support is needed, and who specifically needs support. However, despite these efforts, all professionals acknowledge that they are not able to reach all individuals in the neighborhood, or individuals belonging to their target group. Some neighborhood residents thus continue to remain invisible to the eyes of the working professionals. There are three barriers identified that impede the efforts of professionals in reaching, supporting, and engaging residents in neighborhood projects. We will elaborate on the following barriers now: (1) practical, (2) socio-cultural, and (3) assumption-driven.

### 5.3. Barriers to reaching neighborhood residents

#### 5.3.1. Practical barriers

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*There are so many funds and agencies [within neighborhoods] where you can apply for things. How do you ensure that the right people know the possibilities? It is quite a web of organizations that we are a part of, yet I am not proud of it. It is a pity that you have to say, ‘oh, the contribution goes through the [city pass], and you can request the clothing from us, if you can’t figure it out then you still have [other foundations]’. And you have even more small funds that are accessible.*

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In this excerpt, the representative of the children’s sports fund touches upon a recurring theme in the interviews, namely the enormous number of organizations, funds, and projects in the neighborhood, which is a practical barrier. Most participants indicate that they work together with various professionals in different areas, both at the municipal and neighborhood level. The coordinator of the children’s schooling fund sees this collaboration as an important ‘co-creation’ in which a strong safety net is created. According to one of the researchers involved in the neighborhood project, this collaboration can be seen as a ‘messenger system’ where intermediaries on the ground come in contact with neighborhood residents, and refer them to one of the many organizations within the municipality or neighborhood to help them with their request or problem. Despite the positive comments about the collaboration between the organizations, many participants acknowledge the complexity of it. Both the professionals and the neighborhood residents are caught in a complex web of relations, in which it is often difficult to keep a clear overview (see also Dibi, 2020). The municipality is often involved in neighborhood projects, either by managing projects or



by financially supporting social organizations, associations, funds, initiatives, and projects. Additionally, independent organizations and associations are in contact with the municipality to discuss policies, regulations, and their projects. According to our participants, there are too many organizations where residents can turn to or be referred to for help, which hinders the effectiveness of the projects.

Furthermore, organizations are dealing with a high turnover of volunteers who often do not work on projects for a long period of time. This is a second practical barrier that impedes professionals' efforts to reach and support residents sufficiently. As the coordinator denotes, "whenever people leave, knowledge and experience also disappears". Knowledge about one's own organization, but also about other organizations, associations, and structures within the neighborhood that are crucial to maximizing professionals' efforts. Moreover, the high turnover disrupts the trust of residents in the organization and their professionals, and it is precisely this familiarity and trusting relationship with professionals that is important for residents to get involved in projects. The impediment to this relationship of trust is also related to the following practical barrier.

As aforementioned, time and investment are beneficial for the effectiveness of the projects. However, as many participants admit, the time to commit to and invest in active dialogue with neighborhood residents is lacking. This barrier is echoed by the representative of the children's sport fund, who prescribes the lack of time (and money) as the reason why they are relatively far removed from the residents in the neighborhood. The final practical barrier we identified, also mentioned by Dibi (2020), is the language barrier and illiteracy of some neighborhood residents<sup>7</sup>. The coordinator of the children's schooling fund recognizes this problem and critically reflects on his position as a high-educated Dutch person; what in his eyes may have been written at an understandable language level might still be incomprehensible to those who are lower educated or have limited ability to read in Dutch. The means of communication used by the professionals to reach out to and inform residents are often very textual (e.g., the website, flyers, registration forms), making it difficult for individuals with a language barrier to understand what they have to do or what support they can get (Dibi, 2020). Moreover, due to the reactive approach of some strategies employed by professionals, neighborhood residents often have to seek help themselves through phone consultations, email, or filling in forms. Low literacy and language barriers are hindering factors that raise the threshold to seek help. Interestingly, as the local church support indicates, the informal circuits within neighborhoods are very important as they are used when such language difficulties arise, for example by assisting as a

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<sup>7</sup> It should be noted that the interviews contained specific questions about illiteracy, which steered the answers in a particular direction, while the participants themselves may not have experienced this as a barrier beforehand.



translator during conversations. We now turn to the second barrier that impedes professionals' efforts in reaching, supporting, and engaging residents in neighborhood projects: the socio-cultural barriers.

### 5.3.2. Socio-cultural barriers

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*People often ask 'where are you from?' 'Are you from the tax evasion department?' 'Are you here to check on us?' 'Are you from the news?' 'Are you a journalist?' 'Are you from the municipality?' 'Are you from the housing corporation?' 'Where are you actually from?'*

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This quote from the interview with the local church support sheds light on the distrust residents have towards the authorities. As indicated by Dibi (2020), fear of being evicted from one's house or the possibility of children being taken away by social services hinders residents in trusting professionals in the neighborhood. Distrust as a barrier to involving residents in neighborhood projects is echoed by all interviewees. The representative of the municipality explains that people fear not being heard and helped with the problems they face. To some professionals, it is best to work on the ground with the residents and neighborhood coaches and teams instead of the 'big' municipality. In this way, organizations remain approachable and show that they want to pay attention to the wants and needs of neighborhood residents. Nevertheless, it should be noted that the municipality is important in the network of many organizations as they refer individuals with certain problems to the respective organizations. This 'working together' could then be key to reaching and supporting as many children as possible.

Moreover, social stigmas or labels may impede neighborhood residents in seeking help from the various organizations. For instance, all professionals involved in this study draw upon the notion of 'the vulnerable' when talking about the target population they wish to reach. But who are the vulnerable individuals and how do you define vulnerability? According to Brown (2011), the concept of vulnerability informs how we manage and classify people, yet it is loaded with stigmas and assumptions. This is echoed by a researcher of the neighborhood project: "What is vulnerability? Can you even starkly define it, or is it something that is actually quite broad, counting for many?" Albeit a popular term in the lexicon of everyday life, it literally implies a state of weakness and could be problematic for being oppressive and patronizing. In line with Brown (2011), we indicate that the term should be handled with care. Labels could otherwise prevent professionals from reaching individuals who need help, and discourage those in need from seeking and in turn receiving help, because being vulnerable can be seen as shameful.

At last, the sports broker noticed that some parents and children experience barriers to participate in sports that stem from someone's childhood (e.g., what we have been raised with), education, the cultural discourse



about sport (e.g., in some cultures girls, unlike boys, are not allowed to partake in sports). Together, distrust, shame, upbringing, education, and cultural discourse are socio-cultural barriers that make it more difficult for professionals to engage residents in neighborhood projects. Consequently, lower engagement of neighborhood residents contributes to people remaining or becoming invisible. This brings us to the last barrier discussed in this section: the assumption-driven barriers.

### 5.3.3. Assumption-driven barriers

There are different assumption-driven barriers to reaching, supporting, and involving residents in neighborhood projects, especially those who are invisible. The first assumption-driven barrier concerns the stereotypes professionals have about the neighborhood they work in and its residents. Anecdotally speaking, think about statements such as: this is a deprived neighborhood, residents have a low-income status, the residents are all criminal, that neighborhood looks tatty, and so on. According to the local church support, it is key to have no prejudices or biases about the place you will be working in and the people you are working with. Reflexivity is also mentioned by the municipality as a key factor in reaching neighborhood residents.

The second assumption-driven barrier entails the idea that all neighborhood residents want or need to be helped. In order to then engage all residents in neighborhood projects, professionals need to get rid of biases and assumptions they have about the neighborhoods they work in and its residents, and should ask the residents if they need help at all and make concrete what kind of help they need. Also, as voiced by the representative of the municipality, the intrinsic motivation of organizations to reach particular invisible individuals in neighborhoods should be clear: “Do we want to reach residents because they are missing from our data, or do they actually need the help we offer?” Organizations should then be clear on their motivation to help, which should lay with the individuals in the neighborhood and not in the statistics. Hence, these assumption-driven barriers make it harder to reach, support, and engage residents in neighborhood projects.

## 5.4. Final reflections

This study outlined the strategies explored by professionals in reaching (invisible) residents in neighborhoods in a city in the Netherlands, and provided insight into barriers in engaging residents in neighborhood projects. By interviewing different professionals, we find that different reactive strategies are employed to reach neighborhood residents and involve them in projects and activities organized (e.g., information resources and application processes). Furthermore, different proactive strategies are explored and employed to actively reach out to residents in neighborhoods (e.g., house visits, dialogue, and the



presence method). We also identify that there are three barriers in reaching neighborhood residents, which could particularly make it difficult to reach out to and support invisible residents. These barriers are (1) practical (e.g., too many organizations, high turnover of volunteers, lack of time and money, and language barriers), (2) socio-cultural (e.g., distrust, fear, and social stigmas), and (3) assumption-driven (e.g., stigmas and labels). In order to overcome these barriers, we second pleas from our participants for an integral approach to social welfare work in neighborhoods in the Netherlands and ask for a critical reflection on the strategies used and assumptions with which professionals arrive in the field. In this way, more residents will be reached, supported, and engaged in projects and activities, and ultimately in society.

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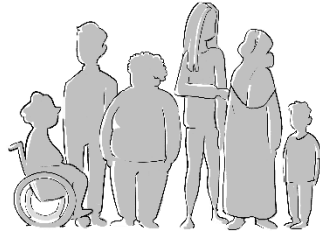
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## Chapter 6. Discussion

There are groups of people who are not represented in data in (academic) research, or fall out of sight of professionals' advocacy efforts and programs as a consequence of their unnoticed complex intersectional identity and social situation. This is problematic as unheard and unseen individuals might not benefit from the innovations and solutions of academic research or the strategies and advocacy efforts implemented by professionals, thereby increasing inequities in society. To address the complexity of this problem we undertook an unusual interdisciplinary pilot project in the contexts of the hospital, the workplace, and the neighborhood. In doing so, this project emphasized the 'Power of One', which underscores the idea that interest in the voices of individuals with complex identities and social positions will help researchers, policymakers, and aid workers to focus on the human being behind the label or category.

Research was conducted through literary desk research and in-depth semi-structured interviews with various professionals in the three contexts. In this discussion chapter we synthesize our findings outlined in the previous chapters. Our main findings are that the professionals we interviewed use a multitude of strategies to reach their target groups but that these can be improved in order to better represent the diversity within these groups. Several barriers are identified that preclude professionals from implementing more proactive strategies at reaching unseen and unheard individuals; they are practical, personal, relational, socio-cultural, and assumption-driven. Understanding the multi-faceted nature of these barriers is an important first step towards ultimately developing solutions. In this first phase of our project, we mainly focused on the perspectives of professionals (i.e., medical professionals in the hospital, HR and D&I professionals in the workplace, and social-welfare professionals working in the neighborhood). In the next project phase, we will turn to unheard and unseen individuals themselves in order to take their perspectives and experiences into account.





## 6.1. The overarching findings

### 6.1.1. Proactive need assessment strategy

In this study, we identified different strategies professionals employ to reach, support, and assess the needs of (invisible) individuals in the three contexts. The strategies differed in the extent to which they were reactive versus proactive. More proactive strategies were less often implemented in comparison to reactive strategies, but do seem promising towards reaching invisible individuals as these actively engage with individuals to offer the correct support. An example of a proactive strategy from the workplace context is the focus on narratives towards change by the D&I manager. She uses stories to learn about the experiences of the employees and utilizes the stories to generate open debate and discussion on sensitive topics and taboos, steering the narrative beyond that of inequality and discrimination towards an inclusive environment. Another strategy proactive in nature is the presence method used by the neighborhood church support. These single strategies thus value the perspectives of (invisible) individuals by asking them about their experiences, what they struggle with, and what they need. Professionals invest time in connecting and building trusting relationships with those they try to reach out to, engage with, or help. In doing so, individuals are not just subjected to the strategies employed by professionals, but are encouraged to speak, influencing the (future) direction of the strategies and the help offered.

There are however a few shortcomings and limitations of the focus on such single strategies. We find that some strategies are, above all, projects focused on achieving intended goals and aims in a specific time frame. A case in point is diversity training to encourage leadership in the workplace. This project is short-term and, if done well, could be a quick fix to problems of inequality and discrimination. A house visit to a family who needs financial support entails just a few hours of conversation. After that, a family either receives the support money or is referred to the next organization that can help them. Again, this is a short visit, offering a relatively quick fix to multifaceted problems that many individuals cope with. The coordinator of the children's schooling fund indicates however that, instead of one-time solutions, structural change needs to be brought about. Due to the project-like nature of most strategies, individuals that need help become 'projects' themselves and are only supported or helped for the duration of the project only. In stating this, we do not overlook the good intentions of professionals but signal that the nature of the projects could affect its success and effectiveness in reaching out to unheard and unseen individuals in different contexts. We also acknowledge that professionals may stumble upon managerial restrictions, run into a wall of bureaucracy (e.g., lack of time and money, or having no policy at all), which hinders their ability to work proactively.



In addition, most strategies fail to take into account the complex intersectional identities of individuals. A more intersectional approach should be employed to understand and assess the needs of individuals as a whole as these intersectional identities affect their perceived experiences. This was exemplified by the representative of the intersectional interest group in the context of the workplace as he reflects on his intersectional identity as a black gay man: “It is about me as an LGBT person, but not about me identifying as LGBT in relation to my blackness. While my LGBT identity is often determined in relation to my blackness”. Hence, because those intersectional complexities are not considered, a particular marginalized group is neither represented nor heard because only a part of their identity is taken into account when strategies are developed and executed. Taken together, we see that proactive strategies are a promising method to learn about the needs of the individuals in groups, however, these strategies can still improve as some are single strategies, more like projects, or miss a focus on the intersecting identities of individuals.

### **6.1.2. Barriers are multifaceted**

Within the three different contexts, we identified various overlapping barriers that complicate reaching and supporting (invisible) individuals, namely practical, personal, relational, socio-cultural, and assumption-driven barriers. First, practical barriers include logistics and complex (organizational) structures which impede the effectiveness of (proactive) strategies, such as the lack of time and money, and the high turnover of medical professionals (hospital) and volunteers (neighborhood). Second, personal barriers both impede and enhance the willingness of individuals to participate or engage in trials, projects, and programs because of personal considerations and motivations (e.g., altruism, (dis)trust, privacy concerns, skepticism, and fear). Third, relational barriers relate to a trusting relationship – or lack thereof – between professionals and individuals, which affect the reaching and support of individuals. Fourth, socio-cultural barriers are influenced by wider societal discourses and attitudes and are imbued with social meaning, stigmas, and stereotypes. We see that trust plays a role in personal, relational, and socio-cultural barriers. Last, assumption-driven barriers are biases and prejudices of professionals about (invisible) individuals, which influence how professionals go about their strategies and who they are trying to reach (e.g., assumptions about why some LGBTQI+ employees stay closeted). For instance, our participants assume that invisible individuals are difficult to reach due to a lack of focus on intersecting identities (e.g., being black *and* gay), or the complex living situations or social status of some individuals (e.g., the poor, homeless, or individuals without a residence permit, and immigrants). These barriers are subjective and fueled by social stigmas and stereotypes.

Based on the assumptions of professionals about the invisible populations, we outline two main reasons for the invisibility of certain individuals in the hospital, workplace and neighborhood domain. The first reason



is that some individuals just do not want support, because they may already feel comfortable in their skin (workplace) or want to cope with their problems on their own (neighborhood). Another reason is that some individuals may want support, but their needs disappear against the social and political discourse in the Netherlands; they do not feel represented in this current climate, or are literally invisible for professionals (e.g., they stay closeted at work, never go to a medical consultation at the hospital, or have no legal status). Professionals working in the three contexts (and beyond) should thus critically reflect on their own biases and take into account the complex intersecting identities and social situations of individuals.

Although many barriers were shared within the three contexts, some barriers hold different meanings in the different contexts. For example, in the workplace and neighborhood context, we identified various socio-cultural barriers that impede the effectiveness of strategies executed by professionals. These barriers include social stigmas and labels about invisible individuals (e.g., closeted LGBTQI+ employees and ‘vulnerable’ neighborhood residents), as well as dominant discourses, such as heteronormativity and the normalization of discriminative remarks. In the context of the hospital, such socio-cultural barriers did not come to the fore during the interviews with the different medical professionals. Although they might indirectly play a role in patient participation in clinical trials, medical professionals did notice them as such. Cultural differences and the position of the physician were however mentioned as socio-cultural barriers to patient participation in clinical trials. All barriers need to be kept in mind by professionals and advocates in order to understand the underlying issues and problems that make it difficult for professionals to reach (invisible) individuals, and for those individuals to let their voices be heard. For now, we showed that the barriers in the hospital, workplace, and neighborhood context are multifaceted and interrelated. The barriers, therefore, need multifaceted solutions to address the complexity of intersecting identities and the social situation that feeds into the invisibility of the unheard and unseen individuals in the three contexts (and beyond).

## **6.2. Reflection on research approach**

As mentioned in the introduction, within the framework of unusual collaborations, our aim was to research new forms of collaboration in science and scholarship. We set out to do this by means of new combinations of people (multidisciplinary), mixed methods (with a particular focus on deeper qualitative investigation), subjects (wicked problems in societal context), and research objectives. When we look at the people who made up our “unusual” collaboration, we can confirm one of our early implicit assumptions: that collaboration works and leads to results; the different disciplines provided rich discussions and also broader perspectives on the three topics than a mono-disciplinary view could have provided. Related to this are the methods of inquiry, the ways we ask questions and obtain answers in analysis and interpretation: throughout the collaboration, we have repeatedly discussed how to approach the three topics, how to frame our



questions, and finally document the obtained results. This led to adjacent developments like the glossary, multifaceted and open-ended interviews, and a conceptual structure that aligns across the three topics.

The second consideration is that unusual collaborations are also experiments in working together and in using diverse, potentially conflicting methods. We can confirm the experimental nature and yet clashes in methodology did not materialize – in part, because we were careful and thorough in our preparations and discussions. The three research contexts that represent the subject matter in this collaboration were chosen to be deliberately “wicked” (Rittel & Webber, 1973) and societally relevant. They pose challenges that hinge on the individual and yet impact the collective. This is essentially the idea behind the “Power of One”, the focus on unseen and unheard individuals in their context, situations, and intersectional identities. From the start of the project a risk of this project was that we would not be able to see the individual in an organization because the organization would somehow shield them off. So, the risk we would not be able to obtain visibility into the different organizations and collectives to investigate in-the-wild. Permeating and investigating an organization’s culture and practices from a critical angle is an intricate endeavor. And again, we found that through iterative engagement with professionals in the targeted organizations, useful insights emerged and became the basis for next inquiries—we were able to investigate in the bounds of reasonable openness and cooperation.

Finally, our research objectives were two-fold from the start, combining (1) research into three specific challenges with (2) a joint meta-research perspective on how we work in a collaborative way. In retrospect, the former objective, to address three research challenges, dominated in most activities. Being able to articulate the second meta-research perspective became more important toward the end: our general approach was driven by the interest in finding new ways to ask new questions from more diverse perspectives as researchers.

Rather than jumping to formulating solutions, we focused on identifying the problems involved in reaching the unheard and unseen in order to understand these efforts. This was driven by the awareness that taking and ‘pushing through’ a potential solution would not only be naive and irresponsible, but inherently conflict with our main driver: addressing the unseen and unheard individual in a sustainable, scalable way – sustainable to ensure long-term impact and scalable to facilitate replication across contexts. It was in the second last session that we were able to articulate this: we did not want to engage in yet another ‘project’, a time-constrained intervention that would solve a problem and leave the system in a fixed state to continue in a better direction. In fact, we reject this way of thinking when it comes to the subject matter of our inquiry: difficult, wicked challenges that play out in unforeseen ways for society and the individual. The outcomes of this project should not be taken as recommendations to solve, but as suggestions to inquire and know more. In fact, we aim to provide evidence that new questions can help unearth unseen strategies and



approaches in a particular domain; not saying though, that these strategies are necessarily better or more appropriate. The domain professionals need to ask themselves different questions to come to answers about strategy choice (reactive or proactive; or a different dimension). This assessment needs to be made through co-design or other participatory techniques by professionals and affected populations. In reflection, in holding back from solving seemingly obvious problems, we were able to sustain and deepen the inquiry touching on nuances that reflect both methods and the ‘long tail’ of individuals.

### **6.3. Limitations of this study**

There are limitations to this study that need critical reflection to improve future research. The first point of reflection is that this study is a pilot project of ten months as part of a (potential) larger study. Although we did what we planned to do during this pilot phase (i.e., talking to professionals in different contexts to discuss the strategies used and the obstacles encountered in reaching (invisible) individuals, and examine their perspectives on these individuals), future research is needed to enable the voices of those we do not hear and see, to encourage the power of one (as the title of this study advocates). The pilot phase is a stepping stone for the continuation of this study, as we first needed to uncover who the unheard and unseen individuals are, and what strategies are currently used to reach out to, support, and engage with them.

The second point of reflection is found in our methodology. The methodological standpoint of this study is qualitative, conducting literary desk research and semi-structured in-depth interviews. Through these methods, we learned about the ways in which the professionals go about their work, but we do not know what is tacitly done or agreed upon, what is implied, but not expressed. Thus, our study fails to establish to what extent what professionals say is actually what they do. A way of addressing this issue could be using participant observation as a research method. Such participant observation would entail joining the professionals in their respective work contexts, being present for a time span of weeks or months, building trust with them, and observing their ways of working. In this way, knowledge can be gained about the intricate dynamics that determine the relationship between individuals, and the complex organizational structures that feed into the social environment of all professional contexts. Future studies could benefit from using participant observation.

### **6.4. Future research directions**

We wish to continue this collaboration in a second phase in which we aim to investigate how the barriers identified in the first phase can be resolved from the perspective of the unheard and unseen. Furthermore, by integrating the perspectives and experiences of (invisible) individuals in the different contexts, we want to critically reflect on the strategies that different professionals employ. We want to further investigate



whether these strategies are effective in reaching, engaging, and supporting the unseen and unheard. Throughout this second phase, a key value we adhere to is ‘nothing about us, without us’, meaning that we wish to include target groups by using co-creation and participatory design methods. We propose three main future research directions for the second phase of The Power of One, which focus on the same three contexts as in the first phase: the hospital, workplace, and neighborhood.

First, data privacy emerged as a barrier in the contexts of the workplace and the hospital. Lack of trust in anonymity was thought to prevent employees from sharing their identities in surveys and patients from enrolling in clinical trials, and doubts about data privacy regulations prevents HR-professionals from asking about sexual orientation and gender identity. We will examine the tension between data privacy and inclusion by, together with LGBTQI+ employees and interest groups, evaluate a poster campaign as a conversation-starter-tool for HR-professionals to discuss sensitive employee data collection (e.g., registering employees’ sexual orientation and gender identity in their digital personnel files, or collecting organizational survey data on the topic). We believe the insights from this project will also be applicable in other situations where marginalized people indicate a lack of trust in data collection. Additionally, we will include this topic in conversations with individuals in other contexts.

Second, technological solutions were raised in our conversations with professionals as a possible solution to reach out to individuals who are currently not included in data collection efforts. Both practical barriers (e.g., lack of time, high turn-over of staff), and assumption-driven barriers (e.g., judgments that a person’s language proficiency is too low) prevent reaching certain individuals, such as possible patients who can enroll in clinical trials, or neighborhood residents who should apply for financial support at funds and organizations. Are there technological solutions to reach these individuals by providing information in a way that meets their needs? In collaboration with a Dutch patient organization, we aim to use participatory design methods to discover ways in which we might remove barriers that thus far prevent the inclusion of hard-to-reach patients in clinical trials. These insights should be useful beyond our project, and provide suggestions to reach unheard and unseen individuals in society. Important to note that technology is not a means to an end as it can raise other issues regarding people with low literacy and low digital skills, as well as privacy and cyber security issues. However, technology ought to be considered a tool to understand the problems individuals encounter.

Third, Eindhoven Engine included the Power of One in a collaboration with the Eindhoven Library with the goal to reach out and understand the needs of a target group of inhabitants of neighborhoods in Eindhoven who face challenges such as low literacy and digitization skills. In this project, a key goal is to examine how we can empower a community to make their needs known to policy makers. These insights should translate to other situations where marginalized individuals need to be empowered – and we will



validate our findings in the context of empowering LGBTQI+ individuals to make themselves heard in the workplace, and empowering patients to express their needs to clinical trial researchers. Each of the three future research directions starts in a different context, as an incubation, and will then gradually shift and incorporate the other contexts. Beyond helping us manage the operational load of researching the three contexts, this will also stimulate stronger collaboration and linking between the three contexts throughout the project.

## 6.5. Final remarks

In this study, we critically engaged with and analyzed strategies employed by professionals to reach out, support, and engage unheard and unseen individuals in the hospital, workplace, and neighborhood context, and address the obstacles they encounter. We think that strategies should be proactive rather than reactive to consider the needs and perspectives of the (invisible) individuals, value trust, and relationships. We also find that proactive long-term investment is a promising method to enable the voices of (invisible) individuals. Furthermore, there are various multidimensional barriers (i.e., practical, personal, relational, social-cultural, assumption-driven) that impede (or enhance) professional efforts. These barriers provide insights into how professionals, and possibly (invisible) individuals, negotiate their identity and navigate society. They also shed light on the social and political discourses that underpin the difficulties in reaching (invisible) individuals and their capacity to have a voice. Additionally, we plead for professionals to be careful in labeling the individuals they work with as the term used could be experienced as patronizing or oppressive. In doing so, we see that objective knowledge can be gained about (invisible) individuals: who they are, what they need, and how they want to be seen. In line with this, we indicate that the intersectional and situational complexities of (invisible) individuals need to be taken into account. We wish for the continuation of this study to address problems regarding the representation of the unheard and unseen in the hospital, workplace, and neighborhood context by focusing on the perspectives of these individuals – for ultimately the power of one to be enabled.

## 6.6. References

Rittel, H. W. J., & Webber, M. M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, 4(2), 155–169. <https://doi.org/10.1007/bf01405730>



# Appendix 1. Meta Report

This midterm meta report describes issues and discussions in the CUCo “Power of one” project related to three themes: logistics, CUCo- and project-specific issues, and disciplines and interdisciplinarity.

## Logistics

- **Finance and governance.** The four institutions, and within the institutions the different faculties or departments, have different finance and governance procedures and structures. This cost a lot of time and work in the beginning of the project. Institutions/departments differ in how easy it is to collaborate across institutional borders. There are also differences in how autonomous the YA members are, e.g., some members have relative freedom in spending their hours whereas others have to account for all fte and need explicit approval of their manager.
- **The importance of the research assistants.** The YA members are in the project for 0.05 or 0.1 fte. A large part of the budget is spent on two research assistants (first we hired one; midway we hired another one) who work 0.8 fte and have a master’s degree. The RA’s prove to be a crucial factor in the project (as acknowledged by project members asking “What would we do without Manon and Anna-Lea?”), because 1) they have a good overview over the project because they spent the most time on it, because they work on all three sub themes and because they conduct the interviews with the participants, and 2) their background is in anthropology which means that they are experts in the methods used in the project, and the discipline of anthropology is very reflexive and acknowledges differences between disciplines and perspectives. One point of discussion, though, is whether it is smart that two MSc-level RA’s play such a crucial role in the project. One project member wondered: “Are they assisting us or are we assisting them?”
- **Ownership and leadership.** Officially there is no PI in the project. This can lead to discussions related to ownership and leadership. Some project members acknowledged that the project is not a priority because of our 0.05 or 0.1 fte, and that it is difficult to make time for the project due to competition of other work priorities. A solution could be to hire a PhD candidate or postdoc to lead the project, but would this help with ownership as well?

## CUCo- and project-specific issues

- **Unusual collaboration.** Questions arose about how unusual our collaboration actually is. Is the combination of our disciplines unusual enough? Also related to our deliverables: "We can allow ourselves to have fun."





- **CUCo board members in the project.** Several project members are also on the CUCo board. On the other hand, this is handy (because of inside information) but it can also be complicated (because of conflicts of interest).

### **Importance of Flatland facilitation and visualizations.**

- **The division in three subprojects.** We decided to answer our overarching research question for three different contexts: the hospital, the workplace, and the neighborhood. Discussions arise about how similar the subprojects can be, and how fixed we should be about this. In the end, we conclude that "We should not define this beforehand because we have to stay open minded" because serendipity is important in interdisciplinary research. The same holds for the visualizations: because the sub projects have different sub questions and approaches (e.g., the hospital subproject focuses more on barriers, where the workplace subproject focuses more on strategies), the visualizations cannot be completely consistent across the board.
- **Diversity among researchers.** While our research group encompasses a diversity of disciplines, diversity in terms of demographic dimensions is limited. Our group includes men and women in different career stages (from recent MA graduate to full professor), we are all white, mainly of Dutch nationality and mainly heterosexual (to name a few examples).

### **Disciplines and interdisciplinarity**

- **The importance of language and communication.** E.g., some terms that are common in one discipline are contested in another; some concepts have different meanings in different disciplines; some disciplines use different words for the same concept. This is one of the reasons for developing the glossary document, and the visualizations by Flatland aid in the process as well. There is a lot of discussion on language and communication, also in relation to our roles as researchers, e.g.,: "We should use the word *we* are most comfortable with." Language and communication are also important to negotiate between the disciplines, e.g., "I will agree with what the group agrees to, I'm not going to stand in the way, but this is not what I'm used to so this is new to me."
- **Different approaches.** Disciplines differ in their approach in answering the research questions, e.g., taking time to analyze or identify the problem, versus preferring to solve the problem. Although we agreed that for this part of the project, the focus should be on problem identification and analysis, it proves to be difficult to ignore problem-solving. This also leads to recurring discussions about our aims and specific research questions, and the disconnect between what we wrote in our research proposal versus what we are doing now. (Interestingly, these disconnects often become apparent through the visualizations by Flatland). In the end one member commented



“I think a lot has changed during the project and that was the intention, to (re)formulate the project while it was going on.”

- **Different research methods.** Most project members do not feel like experts in the method we chose to answer our research question (the research assistants *are* experts in the method used). The extent to which the method differs from our usual research differs per project member, e.g., some members do have experience with qualitative work but not interviews per se, while another even remarks: “We are not allowed to do this in my discipline.”
- **Different output expectations.** The disciplines differ in what the output of our project (i.e., publications) would look like, as well as how output is recognized and rewarded. Discussions arise about whether it is feasible to write one overarching report or whether we should write reports for the three subthemes. Should we publish in academic journals and/or should we focus on science communication (e.g., a newspaper outlet). Should we include reflections on ourselves in our roles as researchers, which is common in some disciplines but unheard of in others? An adjacent problem is that it is difficult to find academic journals that publish such broad interdisciplinary projects, since interdisciplinary journals are often either still ‘narrowly interdisciplinary’ (e.g., only social sciences), or publish meta-pieces on interdisciplinarity. We discussed publishing our work as an opinion piece in a newspaper, but a project member commented “but then we need one opinion.” Discussions about output even lead to discussions about quality, e.g., “I am outside of my comfort zone here because usually I am a perfectionist.” We do agree that the academic publication(s) should be as open access as possible.
- **Contribution of disciplines.** The value of interdisciplinary research is that the integration of different perspectives enriches the project, leading to a more comprehensive understanding of the research problem than one discipline could offer. This vision, and the need for interdisciplinarity, is shared in the group. However, project members can question the relevance of their discipline or perspective, e.g., “But what can my discipline contribute to the other subtheme?”
- **Missing disciplines.** There has been some discussion about whether there are disciplines missing from our project, e.g., a project member remarking that we need a philosopher.

These issues and discussions arose in the first half of the project, i.e., research set-up and the first stages of the work. Future work will focus on the second half of the project, including the integration of disciplinary insights and the three subprojects, as well as how the individual project members experienced the project.



## Appendix 2. Glossary

This glossary consists of important terms that are either immediately relevant to the project *The Power of One* (in orange font) or emerged during our collaboration as concepts that cause confusion because they are used differently in different fields of research (in black font). In addition to improving researchers' understanding of these concepts, the aim of this glossary is to demonstrate that interdisciplinary collaboration requires awareness of the fact that different disciplines produce divergent languages of research. While terms may look the same, they can have very different connotations or even denotations. For this reason, no interdisciplinary research project can do without a proper awareness of one's own disciplinary language and of the existence of a wide variety of other languages. It is in the same vein that this list contains occasional terms or words in Dutch, which are difficult to translate because they are inherently connected with the Dutch context of this project.

Rather than suggesting that we have come to an agreement on all definitions, this glossary furthermore indicates where we did not find consensus, by raising questions. We hope that it will be treated and kept alive as a living document by researchers of spin-off projects, who are invited to add terms, complement definitions, and raise new questions as they see fit.

- **active citizenship:** new form of governance of Western or Northern European welfare states in which citizens are expected to take personal responsibility for their employability, health, and finances.
- **altruism:** “disinterested or selfless concern for the well-being of others, esp. as a principle of action” (OED). Does it exist?
- **barriers:** factors that prevent people from being seen/heard, including lack of trust, costs, low-literacy, perceptions on privacy, but also preconceptions and blind spots on the part of researchers, workplace professionals and aid workers. The project has mainly focused on the barriers that are experienced by professionals, researchers and aid workers.
- **bias:** preconceived opinion, prejudice, especially regarding groups of people. Important obstacle in academic research, as well as in (medical) care and social work
- **Implicit:** also often referred to as unconscious, though not exactly the same; very (if not most) common form of bias.
- **collaboration:** united labor to achieve a single shared goal.
- **cooperation:** can be used synonymously with collaboration, but often used in a broader sense: working together to achieve your own goal.



- **data:** raw and unorganized facts, not yet interpreted, which would turn data into information and/or knowledge.
  - qualitative: data in narrative form, collected by means of interviews, questionnaires, participant observations, and other methods.
  - quantitative: facts or figures, data, collected in numerical form to be analyzed using quantitative, possibly statistical means.
  - Machine-readable digitization of signals in the natural environment as sensor data.
- **desk research:** characterized by the secondary nature of the data. Research one can do from behind one's desk, thus using reports written by others on data already collected rather than collecting data yourself. It is sometimes referred to as secondary research.
- **disciplinarity**, varieties of
  - Inter-: integration of disciplinary insights to reach a more comprehensive understanding of a complex theme.
  - cross-: synonym for inter- mostly used in the United States.
  - trans-: collaboration/cooperation with non-academic partners.
  - multi-: collaboration/cooperation but no integration.
- **discipline:** institutionalized branch of learning. Not self-evident, but a product of a specific time and place.
- **domains:**
  - Hospital: the place one receives specialized health care, in this project especially focused on people with rheumatism (as group often overlooked in research)
  - Workplace: the physical or online space where one works, in this project especially focused on LGBTQI+ employees (as group often overlooked in research, policy, and advocacy efforts).
  - Neighborhood: the district where one lives, in this project especially focused on vulnerable people overlooked in research and neighborhood projects).
- **ERG:** Employee Research Group/Business network groups/Employee network groups. Voluntary groups, usually initiated and led by employees who share an identity characteristic (e.g., ethnicity, sexual orientation), with the aim to foster a diverse and inclusive workplace.
- **ethics application/ethical approval application:** application for approval to conduct research on human subjects (e.g., interview participants).
- **gender:** culturally constructed characteristics assigned to or associated with people's sex.
- **gender identity:** a person's sense of their own gender.



- **health:** being free from illness or injury. Desire to be healthy is often taken for granted but not self-evident or true for everyone. Is it an absolute or a relative concept? Used to discriminate against groups and de-normalize?
- **health literacy:** the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions. (See also “illiteracy and low literacy”).
- **homogeneity and heterogeneity of research samples:** some disciplines assume heterogeneity (i.e. a cross-section of society) is more desirable because conclusions are more representative of society; others strive for homogeneity because the chance of a significant statistical effect is larger.
- **hypothesis:** supposition that needs to be proven or disproved. Starting point of research, used in all areas of academic research, albeit in very different ways; derived from a research question.
- **illiteracy and low literacy:** having trouble processing textual information and filling out forms; can also be used in specific contexts, for instance “computer literacy”. See also “health literacy”.
- **impact:** effect of research beyond academia. Difficult to measure, both quantitatively and qualitatively.
- **inclusive research:** research that aims to be inclusive, for example by including groups of people from a wide variety of social or (socio-)demographic backgrounds. The assumption is that inclusive research will benefit society at large. Inclusive research also requires inclusive research teams.
- **intersecting demographics:** intersecting aspects of the composition of populations, pertaining to, for instance, gender, age, sexual orientation, education, migration background, race.
- **intersection:** combination of personal identities/characteristics which problematize neat categorization. Important reason why people with complex problems are not seen or heard.
- **key informants:** mediators, people who are part of different domains, who can connect people from the target group to researchers (*buurtwerkers*).
- **lack of representation:** being overlooked or deliberately ignored in research, i.e., in statistics.
- **language:** system of communication used by a particular country, community, social or professional group, like scientists and scholars; visual vs textual, formal vs informal, often taken for granted, but typical obstacle in multidisciplinary research and in identifying as well as reaching the unseen and unheard.
- **lgbtqi+ (and variants):** lesbian, gay, bisexual, transgender, queer, intersex, and other identities
- **linear process:** going forward step by step, not iterative, static.
- **local community:** local coherent groups - not only geographically but also socially - for example a sports community.



- **Migratieachtergrond, persoon met.** Term die ‘allochtoon’ vervangt. “persoon van wie ten minste één ouder in het buitenland is geboren. Er wordt onderscheid gemaakt tussen personen die zelf in het buitenland zijn geboren (de eerste generatie) en personen die in Nederland zijn geboren maar van wie ten minste 1 ouder in het buitenland is geboren (de tweede generatie). Ook wordt onderscheid gemaakt tussen personen met een westerse migratieachtergrond en personen met een niet-westerse migratieachtergrond” (CBS)
- **minority group:** group of people who are either numerically in the minority based on an identity characteristic (e.g., LGBTQI+ employees relative to cis-hetero employees) or who are “minoritized” or “marginalized” on the basis of that identity characteristic, because it is considered a sign of inferiority
- **narrative:** story. Telling of true or fictional event, or a mixture between the two. See also data, qualitative. Allows the individual to demonstrate their human significance. Manifestation of “the power of one”.
- **othering:** the way one constructs ‘us’ versus ‘them’ (Edward Said/postcolonialism) - something we should be aware of, especially regarding its patronizing and alienating effects, and will be part of our recommendations.
- **output:** (academic) publications in a great variety of forms and via different platforms. Means to the end of furthering human knowledge, but often treated as an end in and of itself.
- **project:** currently, the dominant way to organize academic research. Characterized by (interdisciplinary) focus and constraints of time and budget. Well-suited to address topical and relatively short-term issues, but less so for problems that are of a fundamental and long-term nature.
- **projectification:** see also: project. Development that is part of the way in which much if not most university research is currently funded.
- **preliminary/pilot interview:** Conducted to set up a topic list for the interviews and identify people to be interviewed.
- **qualitative research:** use of methods such as participant observation, interviewing, and case studies, to understand the meaning people have constructed, that is, how people make sense of their world and experiences they have in the world. Qualitative research then generally starts with the assumption that individuals have an active role in the construction of social reality and that research methods should capture this process of social construction.
- **question:**
  - open: yields longer, narrative answers, hard to extrapolate
  - closed: yields short answers that can be processed in generalized form



- **Reactive and proactive** approaches. Approaches of researchers, aid workers, and workplace professionals that are either passive, in the sense that potential patients, clients, and other individuals (the unseen and unheard) are expected to actively seek help (reactive) or active, in the sense that researchers and providers of aid actively seek out the unseen and unheard.
- **referring partners:** medical doctors from the same clinical field, but who work in non-academic hospitals, usually in community hospitals. They provide data and intellectual expertise.
- **scholarship:** can be used to denote both science and the humanities, but typically used for humanities research.
- **science:** natural, social, formal, and applied sciences. Does not include humanities scholarship. In Dutch typically but erroneously used as a translation for “*wetenschap*”, which is much more inclusive than “science.” Also true for ‘scientist,’ ‘scientific’ etc.
- **“hard” and “soft”:** often used colloquially to distinguish between sciences among other things, but metaphor carries pejorative overtones (i.e., “hard” is more effective, masculine; “soft” is feminine, less “scientific”).
- **semi-structured interview:** interview for which questions do not have to be prepared in great detail, asked in a specific order, and not necessarily all of the questions have to be asked - depending on how the interview goes
- **sex: (Dutch: *geslacht*)** set of biological and physical characteristics often confused with gender. Often thought of as binary (male vs. female) but in reality more diverse.
- **Sexual orientation:** sexual attraction towards people regardless of gender or sex.
- **shared recommendations:** advice on how to include unseen people in research in the three domains. Integration will take place after separate recommendations: advice on how to include the unseen and unheard in research per domain.
- **shared space:** space for interdisciplinary communication: in our case Google docs, Slack.
- **solution:** buzzword in corporate communication. Something to strive for, also in the context of this project, but often understood in simplistic ways. A solution can also be the cause of new problems; a perceived solution can prevent people (including academic researchers) from further reflecting on the complexity of problems.
- **strategy:** we applied different methods as part of our strategy to identify and (later) reach the unseen/unheard, for example desk research and interviews with HR (human resources) professionals and organizations to collect individual narratives. Overview of steps that need to be taken.



- **target audience:** could be fellow-researchers and the people we would like to interview, or the unseen and unheard.
- **tissue sample:** sample taken from a patient (i.e., blood or urine) in a lab, compare lab test or population sample, different from just “sample” as in random check.
- **topic list:** also referred to as an interview guide, is a document in which topics and related questions are formulated that give direction to the interview.
- **trust:** lack of it identified as one of the main barriers (in all three domains: hospital, workplace, and neighborhood) that prevent the unseen and unheard from actively seeking help or passively responding to calls of social workers and researchers.
- **unseen/unheard in research:** the people (individuals as well as groups) who currently fall between the cracks and are not receiving the help they need, either because they are not seen and heard by relief agencies and workplace professionals or because they are (unwittingly) ignored by medical researchers. Practically, but also philosophically very difficult to identify and reach. This project aims to chart the barriers that prevent social workers and researchers from recognizing the unseen and unheard.
- **vulnerability:** not being seen or heard by researchers, workplace professionals or aid workers when this is needed.
- **wellbeing:** positive mental health, happiness. How can this be measured? Where lies the responsibility for achieving this?
- **zelfredzaamheid:** self-reliance, principle that was embraced by the previous government. Their over-estimation of people’s ability to take care of themselves without relying on professional care has caused many vulnerable people to fall through the cracks.



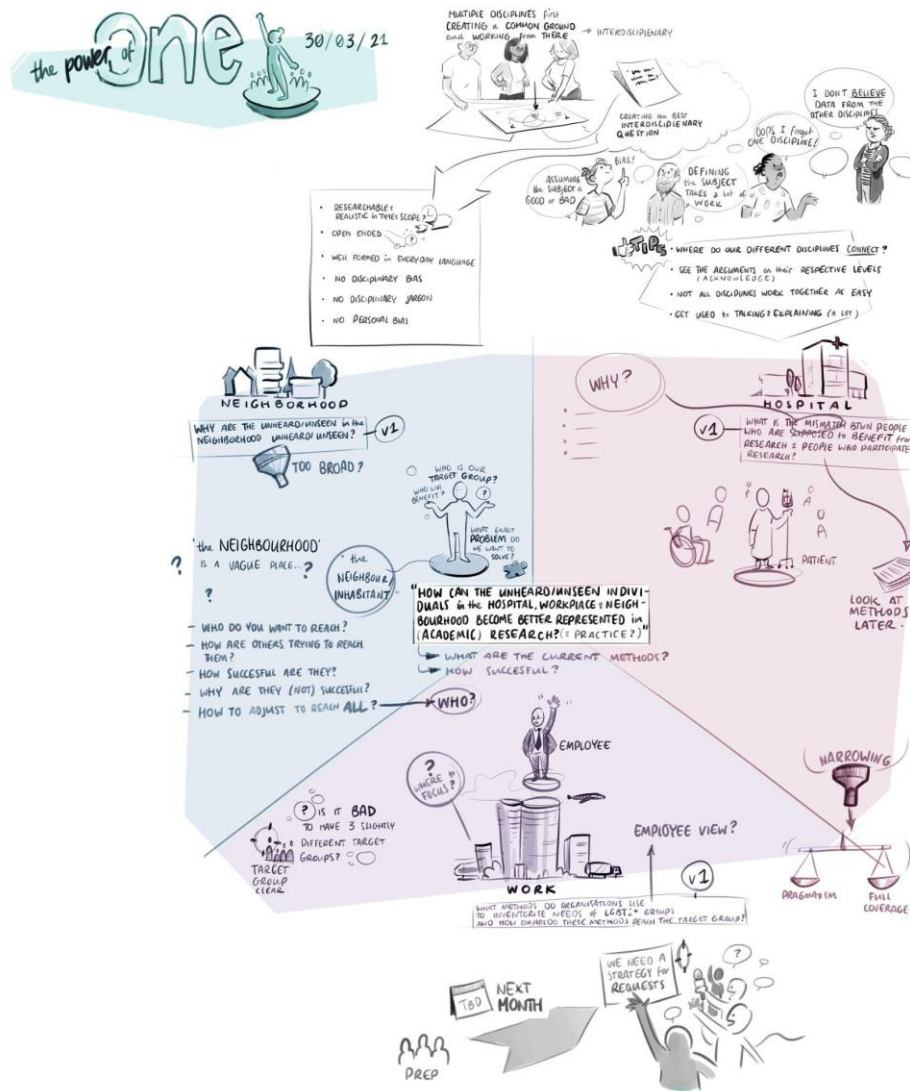


# Appendix 3. Visual Illustrations by Flatland

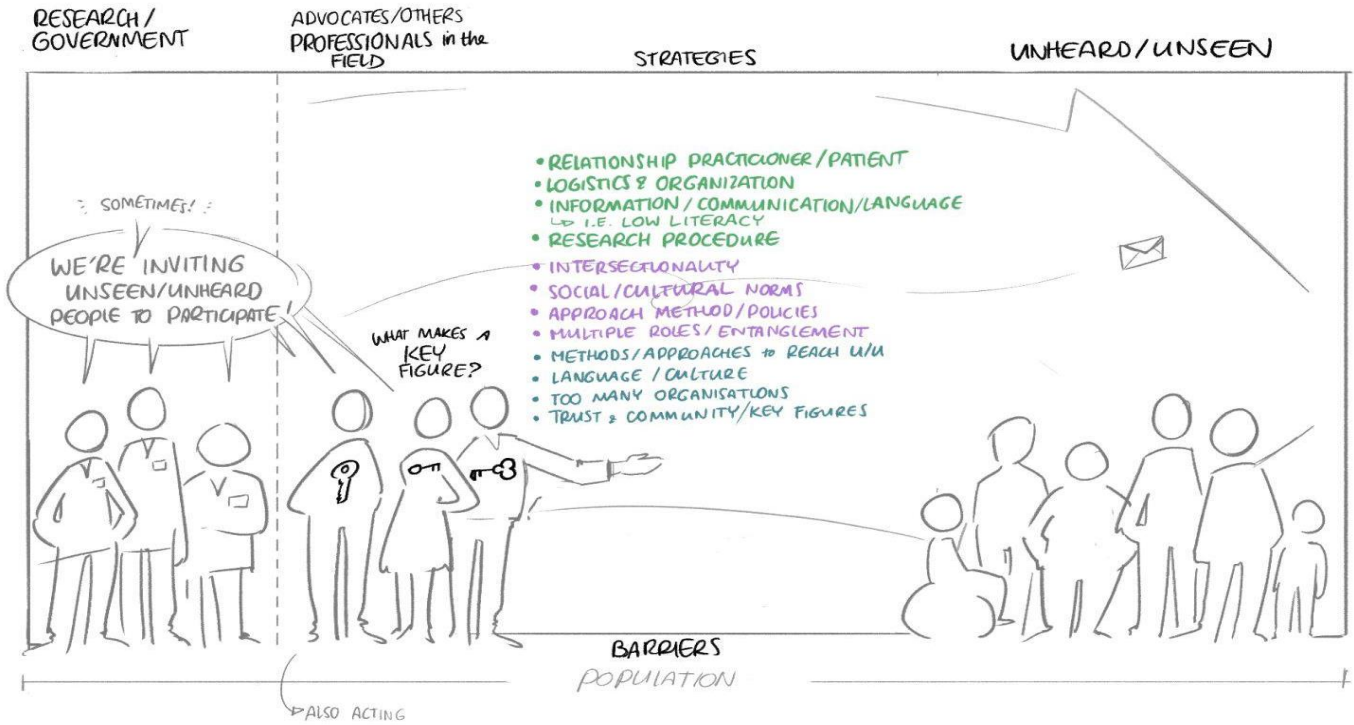
The following visual illustrations are made by Flatland agency and showcase the process, content, and progress of our study. The first visualizations concern recaps of various plenary sessions held with all team members for interdisciplinary discussion and collaboration to take place. The second visualizations are made in preparation for the plenary session, individually with the research assistants or with the context specific teams. These visuals specifically zoom in on the process of our study.

## 3.1. Visual illustrations: Recap plenary sessions

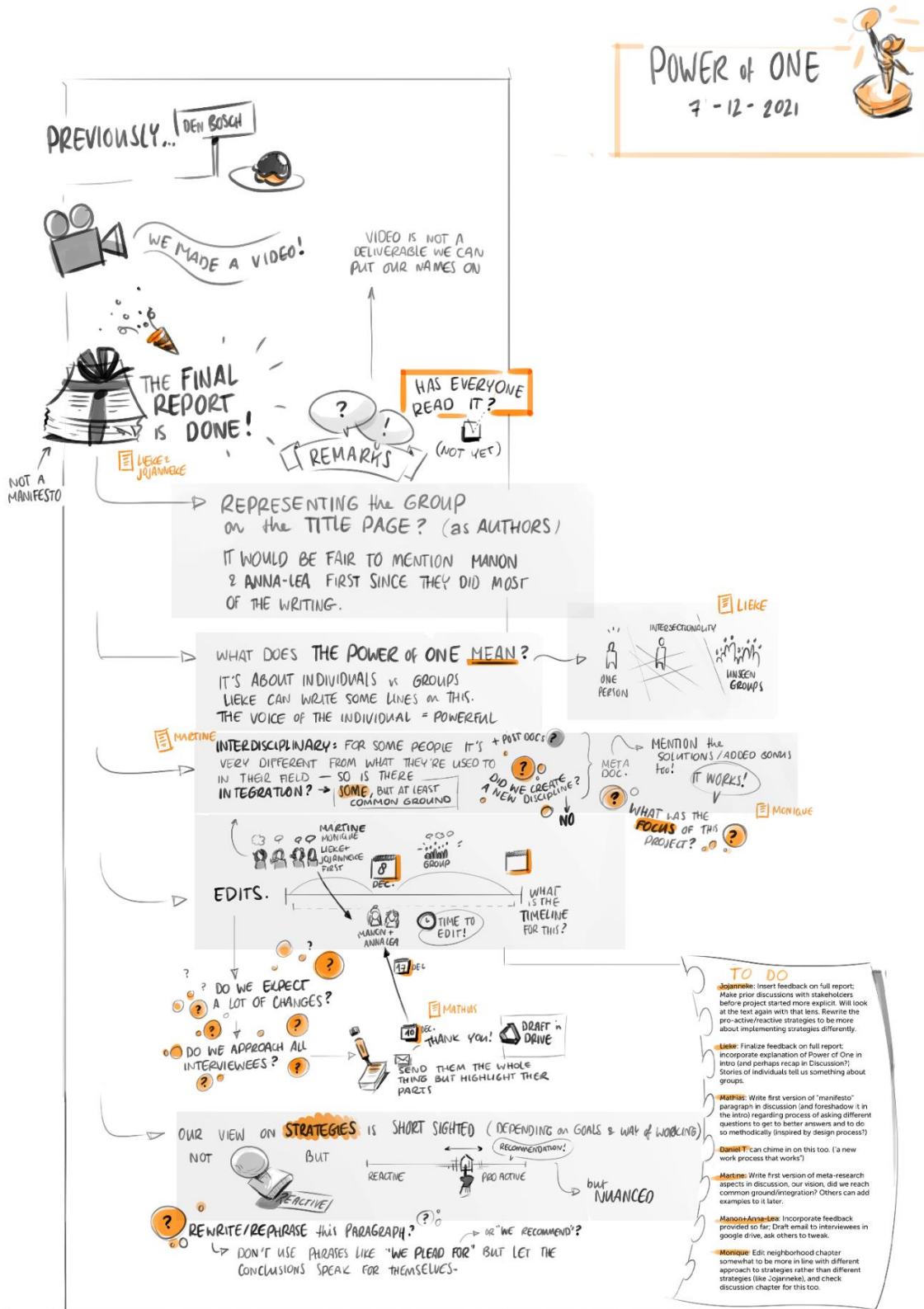
Visual 1: recap of the first plenary team meeting of the power of one project



Visual 2: Recap of fifth plenary team meeting of the power of one project



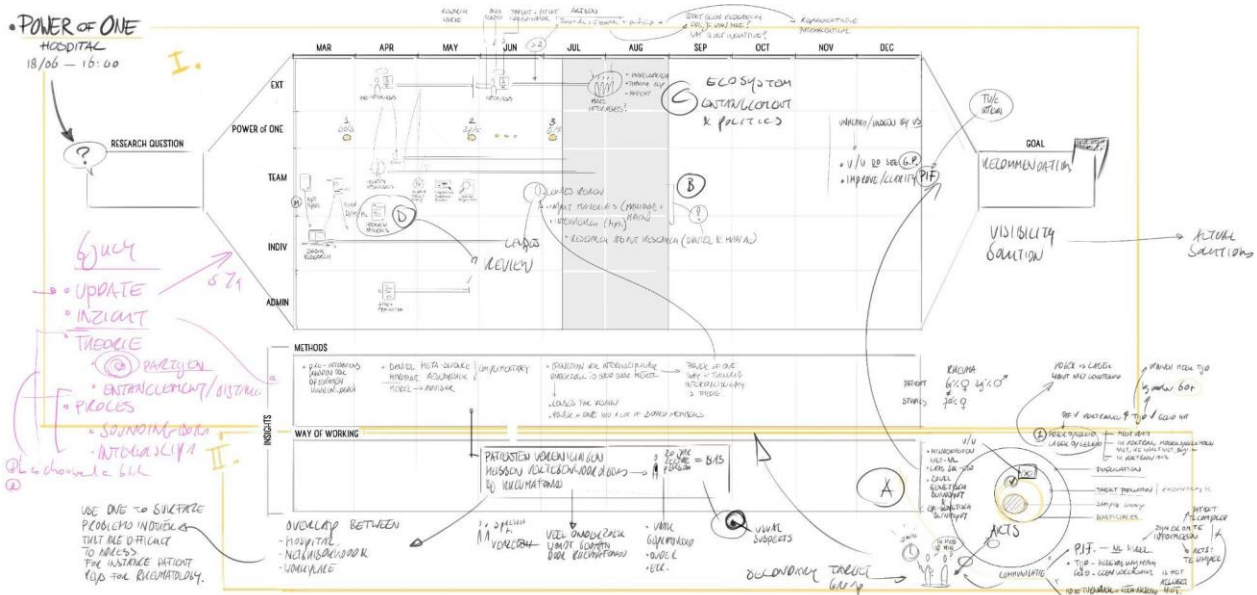
Visual 3: Recap of the final plenary team meeting of the power of one project



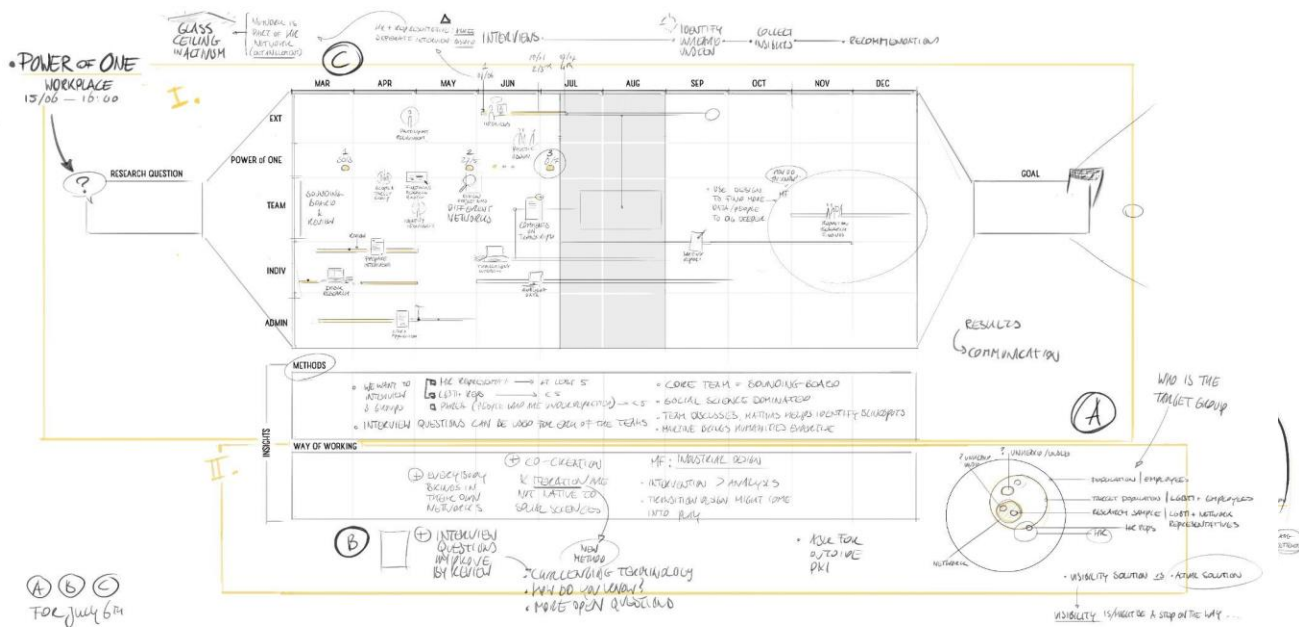
### 3.2. Visual illustrations: The preparation process

The following visuals were made during separate team sessions for each of the contexts of the power of one project, that is, the hospital, the workplace and the neighborhood context. The visuals shed light on the research process and content for each of the contexts.

Visual 4: Process of hospital context



Visual 5: Process of workplace context



Visual 6: Process of neighborhood context

